PARTICIPANTS' DESCRIPTIONS OF LIVING WITH FIBROMYALGIA:
AN INTERPRETIVE DESCRIPTIVE STUDY

by

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ABSTRACT

Fibromyalgia (FM) is a chronic pain syndrome that affects almost every aspect of a person’s life and creates many demands on health care resources. We know very little, however, about what the experience of living with FM is like, from the perspective of afflicted individuals. This study addresses this gap in our knowledge, using the interpretive descriptive method described by Thorne, Reimer Kirkham, and MacDonald-Emes (1997) to elicit individuals’ descriptions of their experiences of living with FM. The analytic framework that guided this inquiry was derived from the existing body of literature that addresses the experience of living with the condition. This literature was then compared with the findings of the current study to capture the essence of living with the phenomenon within the general context of the lives of the participants.

Purposive theoretical sampling was used in this study. The researcher collected data through in-depth, semi-structured interviews with a total of eight participants ranging in age from 31 to 79 years. The data were collected and analyzed concurrently using a constant comparative inductive analytic method.

The findings of this study indicate that key aspects of individuals’ experiences of living with FM consist of several interrelated major themes. One such theme is living with the symptoms of FM and enduring the subsequent impact of these symptoms on multiple facets of the participants’ physical, emotional, mental, familial, social, working, recreational and economic lives. The second theme is the management of FM, which involves the key aspect of striving to achieve and maintain a balance. The third theme focuses on how the social, health care and political contexts shape the experience of individuals living with FM. The findings of this study suggest that persons with FM believe that there is a need for more
education about the condition, especially among health care professionals; this would increase their effectiveness in caring for people with FM. Participants in this study felt that health care professionals need to acknowledge the suffering of individuals with FM, and to strive to support them in their efforts to live and manage the condition.
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CHAPTER ONE: INTRODUCTION

Background to the Problem

Fibromyalgia (FM) is a chronic health condition that presents with generalized muscular aches and pains and a wide range of other symptoms (Boissevain & McCain, 1991a; Gerecz-Simon & Buchanan, 1991; Hallberg & Carlsson, 2000). It affects almost every aspect of a person's life and entails physical, personal, emotional, social and psychological challenges over the course of the illness. While FM is not a fatal condition, it is a chronic illness, and as such it poses significant challenges and costs to the health care system. Individuals with the condition not only live with disabilities and reduced productivity, but their symptoms also require extensive medical and allied health care interventions (Gremillion, 1998; Haines, Blair & Osborn, 1997; Inanici & Yunus, 2002; Oliver, Cronan, Walen & Tomita, 2001).

FM is a chronic pain syndrome, the symptoms of which patients have reported for decades, but was only identified as a clinical entity in the early 1980s (Wolfe, 1994b). It affects about 3-6% of the population in North America (Smythe, Bennett & Wolfe, 1993), and an estimated 5% of Canadians (British Columbia Fibromyalgia Society, 2000). Most sufferers of FM are women aged 50-69 years (Harvey, Cadena & Dunlap, 1993; Robertson, 1999; Wolfe, Ross, Anderson, Russell & Herbert, 1995). Research studies have concluded that FM also affects children and adolescents, whose chief complaint is unusually sore muscles after playing sports (Burckhardt, Clark & Bennett, 2001; Johnson, Collo, Finch & Felicetta, 1990).

FM is a condition that has no known etiology, cure, or prognosis, and its myriad symptoms progress over the course of the afflicted person's life (Boissevain & McCain,
1991a). These symptoms may appear randomly, and their severity varies among individuals who have the same illness (Henriksson, 1995a; Mannerkorpi, Kroksmark & Ekdahl, 1999; Sturge-Jacobs, 2002). As well, a number of studies note that the symptoms fluctuate in intensity throughout the day and from day to day (Prince, Bernard & Edsall, 2000; Sturge-Jacobs). The degree of pain and muscular stiffness typically varies between the acute and less acute phases (Asbring, 2001; Bradley & Alacron, 1997; Littlejohn, 2001; Wolfe, Smythe & Yunus, 1990).

The most common symptoms of FM are chronic, diffuse, generalized musculoskeletal pain, aches, and stiffness that occur in the absence of joint inflammation or tissue damage (Anonymous, 2000; Boissevain & McCain, 1991a; Inanici & Yunus, 2002; Johnson et al., 1990; Wolfe et al., 1995). Additional symptoms of FM vary and may include tenderness, fatigue, short-term memory problems, depression, headache, sensitivity to light, sound and smells, total body aches, associated cognitive dysfunction, migraine headaches, and a disruptive non-restorative sleep syndrome (Bennett, 1996a, b; Boissevain & McCain, 1991a; Johnson et al., 1990; Vanderhaeghe, 2000). These findings are congruent with those of a number of studies indicating that many other symptoms, apart from pain, such as fatigue, muscle stiffness, poor sleep, impaired concentration and irritable bowel are also common to FM (Bernard, Prince & Edsall, 2000b; Gerecz-Simon & Buchanan, 1991; Hallberg & Carlsson, 2000; Henriksson & Burckhardt, 1996; Soderberg, Lundman & Norberg, 1999). Sicca (dry eyes) and xerostomia (dry mouth) are also some fairly common symptoms (Gerecz-Simon & Buchanan, 1991; Smith, 1998).

The symptoms of FM are relatively stable over time, but individuals may experience "flare-up": a period of time when there is an exacerbation of the symptoms of
FM and when the affected individuals feel their symptoms more acutely. This state appears to be brought about by changes in the weather, lights, noise, repetitive motion, and emotional and physical stress (Littlejohn, 2001; Waylonis & Heck, 1992).

Since such a wide constellation of vague symptoms is typical of many other conditions, most patients with FM will have seen several physicians and will have had to undergo many medical investigations before their condition is correctly diagnosed (Bennett, 1993; Henriksson, 1995a; Schaefer, 1995a). Careful physical examination and tests must rule out anemia, infection, hypothyroidism, cancer and other conditions that may produce weakness, fatigue and headaches (Anonymous, 1998). Rheumatoid arthritis (RA), hypothyroidism, cervical and low back degenerative disease, and chronic fatigue syndrome (CFS) all have symptoms that resemble those of FM; these also must be ruled out before a diagnosis of FM may be confirmed (Dunkin, 1997; Goldenberg, 1995; Maurizio & Rogers, 1997; Schaefer, 1995a; Slavkin, 1997). CFS and FM are particularly similar. Both conditions rely on individuals’ self-reported symptoms with no specific objective laboratory or radiological markers to make the diagnosis (Anonymous 1998; Van Heck, 2002). In addition, these syndromes share a number of common symptoms, including sleeping problems, headaches, fatigue, depression and impaired memory or concentration, so it may be difficult to differentiate between the two conditions. The essential difference is that while pain is the hallmark of FM, the hallmark of CFS is fatigue that is present for more than six months accompanied by muscle pain, multi-joint pain and other signs of systemic disease such as tender cervical or axillary lymph nodes (Klippel, 2001).
Unlike many other kinds of chronic pain, pain in FM lacks any specific, distinct pathophysiologies. The pain sites in individuals with FM are usually located at the fibrous tissues—muscles, ligaments and tendons—which however do not display signs of inflammation or any histologic or specific cellular aberrations (Anonymous, 2000; Burckhardt, Jones & Clark, 1998). To date, the only physical criteria generally accepted for diagnosis are the “tender points” that Wolfe et al. (1990) document. Littlejohn (2001) defines these tender points as histologically normal “areas in the body that have been found by empirical observation to be more sensitive to gentle palpation than surrounding regions...[when applying]...a force of around four kilograms per square centimeter equating to blanching of the thumb or fingernail” (p. 328). This digital pressure is quantified by using an algometer (Fischer, 1997). The difficulty in reaching a diagnosis also increases the time before the individuals can commence effective treatment (Bennett, 1993; Wolfe, 1994b). Consequently, patients with FM report feelings of relief when a diagnosis is established, because they often experience the lengthy medical investigations needed to establish the diagnosis as a painful process (Gremillion, 1998; Hughes, 1999; Sturge-Jacobs, 2002).

In situations without underlying pathophysiology, researchers have found it problematic to rely only on the symptom of pain to validate conditions (Eccleston, Williams, & Rogers, 1997; Scudds & Li, 1997). Hallberg and Carlsson (1998) further assert that “due to the subjective nature of pain, it can hardly be directly measured or observed. Instead, pain is verbally communicated and/or behaviorally expressed and therefore must be interpreted by others” (p. 95). It is thus difficult for others to validate or quantify pain, and especially chronic pain, through either direct observation or
measurement, because it is “a complex, personal, subjective and unpleasant sensory and perceptual experience that may or may not have any correlation with bodily injury or tissue damage” (Aronoff, as cited in Hughes, 1999, p.18). Moreover, according to Disney (2000) and Hughes (2002), sociocultural, physiological, and psychological variables may influence the perception of pain in patients with FM.

As well as being difficult to diagnose, the treatment of FM is also not fully understood by health care professionals, including nurses who need to fully understand how FM affects the lives of individuals living with it. Moreover, as Webster (2000) notes, “nurses specializing in the care of patients with chronic pain/FM have perspectives that differ from other caregivers and from patients with FM” (p. 252). Finally, many individuals with FM speak of the importance of educating their significant others, their primary care physicians, their friends, and others about their condition (Bernard, Prince & Edsall, 2000b; Sturge-Jacobs, 2002).

Some studies have observed that many physicians favour the curative model of medicine and prefer to treat people with diseases or conditions that have distinct clinical signs and symptoms based on objective biomedical criteria (Hellstrom, Bullington, Karlsson, Lindqvist & Mattsson, 1999; Sylvain & Talbot, 2002). FM, however, includes a wide range of vague symptoms that seem to fit the descriptions of many psychiatric conditions. These include anxiety, depression, chronic pain, insomnia, irritability, loss of interest, and preoccupation with bodily functions.

Some health care professionals question the existence of the syndrome and look at the condition from the perspective of a psychological rather than a biomedical model (Aaron, Bradley & Alarcon, 1996; Anonymous, 2000; Walker et al., 1997). Some health
care professionals, for example, agree with Hadler (1996b), who states that “the label ‘fibromyalgia’ is a contrivance that harms the patient...[since it] describes physical complaints that all humans associate with being out of sorts and magnifies those complaints into a full-blown syndrome” (p. 85). The case for this view is often strengthened by two observations: first, that the “tender points” criteria were not developed for diagnosis but for the classification of suitable subjects for research studies of the condition; and second, that the pain of the “tender points” may be simulated by persons who do not have the syndrome (Khostanteen, Tunks, Goldsmith & Ennis, 2000; Smythe, 2000).

Sometimes, those health care providers who reject the diagnosis of FM go so far as to categorize the pain of persons with FM as psychosomatic and related to care-seeking behavior, rather than to actual illness (Aaron et al., 1996; Carey et al., 1995; Jones, 2001, Maurzio & Rogers, 1997). Encounters with physicians who have adopted this attitude often cause problems for patients with FM; many have reported negative contacts with health care providers who have limited knowledge about the condition and who do not take the vague signs and symptoms seriously but, instead, label patients as malingerers or “psych cases” (Smith, 1998; Webster, 2000). With the medical community divided over accepting FM as a legitimate medical condition, it is not surprising that the public at large offers less than full recognition of the condition.

After diagnosis, individuals with FM and their families have to deal with the realities of living with this chronic condition. According to Thorne (1993), living with chronic illness may entail the need to “…maintain or improve existing level of strength, comfort, symptom control, weight or mobility—whatever symbolized health in the
context of their own disease” (p.42). Some of the challenges that persons with FM encounter include changes in lifestyles, threats to self-esteem, loss of employment, the disruption of usual roles and altered family relationships. People with FM also experience fear, depression, helplessness, anger, alienation and lack of understanding from their families, friends and others about their condition (Paulson, Danielson & Soderberg, 2002; Sturge-Jacobs, 2002). Many people with FM claim disability benefits because of the difficulty they experience in continuing with repetitive motor tasks due to increasing pain and fatigue, a reduced energy level that requires them to take more time to accomplish tasks, the loss of mental alertness, and the pain of prolonged sitting or standing. All of these factors lead to erratic performance and frequent absences from work (Bennett, 1995). Besides altering the quality of life of those affected with FM, and their significant others (Chenhall, 1998), this condition has significant societal costs as well. A few studies have estimated that the search for a diagnosis, treatments and drug therapies, and lost time costs due to FM have amounted to many millions of dollars (Rogers & Maurizio, 2000; Spencer, 1992).

Problem Statement and Purpose of the Study

Over the past 20 years, an increasing number of researchers have looked at the chronic illness experience from an “insider’s” perspective, attempting to understand the afflicted individuals as they live with chronic conditions in specific relational and social contexts (Thorne & Paterson, 2000). While there is an abundance of literature that looks at other chronic illnesses from this perspective, and some studies that examine aspects of individuals’ experiences of FM such as symptom experience and quality of life (Burckhardt, Clark & Bennett, 1993; Henriksson, 1994; Prince et al., 2000; Soderberg &
Lundman, 2001), most FM research to date has focused predominantly on the definition of fibromyalgia, possible etiological factors associated with it (Aaron, Bradley & Alacron, 1997; Kosek, Ekholm & Hansson, 1996; Maurizio & Rogers, 1997); symptom management (Adams & Sim, 1998; Henderson, 2002; Jones, 2001) and the health status, physical and disability functioning outcome measures associated with the condition of the individuals (Henriksson & Burckhardt, 1996; Henriksson, Gundmark, Bengtsson & Ek, 1992; Ledingham, Doherty & Doherty, 1993). Therefore, relatively little is known about the multifaceted aspects of living with FM within the context of daily life.

This qualitative study addresses the gap in our knowledge of the individual’s perspective on living with FM, with the aim of improving our understanding of the condition and our ability to provide better care for such patients.

Research Question

Given the gaps in our knowledge of FM, and since, in particular, we know very little about what individuals experience when they live with this chronic condition within the context of their general lives, the main purpose of this study was to elicit how individuals with FM describe their experiences of living it. The research question explored in this study is: “How do individuals describe their experiences of living with fibromyalgia?”

Significance of the Study

The practical significance of this study is clear when one considers the chronic but almost invisible nature of FM. A qualitative study such as this one contributes valuable information about the experience of those who must live with the symptoms and consequences of FM, but whose suffering may be viewed with skepticism by some
friends, family members, and even health professionals. Moreover, in spite of medical
treatment, most individuals suffering from FM experience persistent pain, which forces
them to go through various transitions in their personal, physical, familial, social,
psychological, working, and financial lives. As several researchers have recently noted,
these changes inevitably lead to a poorer overall quality of life (Henriksson, 1994;
Schaefer, 1995a, b; Soderberg & Lundman, 2001). This study attempts to elicit
information from people with FM about the specific ways in which the condition affects
their quality of life.

As the symptoms of FM are non-specific, invisible, and subjective, physicians
find it difficult to arrive at an early diagnosis, and therefore tend to under-report or
misdiagnose the condition (Bennett, Smythe & Wolfe, 1992; Goldenberg 1987, 1995). In
addition, individuals affected tend to look well outwardly, so it is hard for professionals,
friends, relatives, and employers to fully believe or appreciate that those affected are
indeed in pain and are experiencing physical limitations, particularly in the absence of
clinical markers, as is characteristic of FM (Soderberg & Lundman, 2001; Soderberg et
al., 1999; Vanderhaeghe, 2000).

Few studies have examined the interactions of health care professionals and
patients with FM, although Hellstrom, Bullington, Karlsson, Lindqvist and Mattsson
(1998) conducted a phenomenological study in Sweden to elicit general practitioners’ and
rheumatologists’ understanding of the phenomenon of FM. These scholars’ findings
showed that doctors had to manage the clinical uncertainty of patients with FM who
looked so well and yet were reporting feeling generalized aches and pain. When the
symptoms are invisible and do not fit with any biomedical paradigm to explain their
cause, some doctors may be unwilling to acknowledge the reality or extent of the patient’s suffering. This unwillingness may well have an adverse effect on the relationship between health care provider and patient.

Health care providers do have an important role in the management of chronic illness; however, the nature of that role may be complicated when professionals are ambivalent about, or disinclined to arrive at, a diagnosis of FM. For this and other reasons, many people with FM have negative attitudes about their health care providers (Webster, 2000). These feelings might affect their attitudes about themselves and their personal efficacy in better managing their condition in order to improve the quality of their lives (Bernard et al., 2000b; Henriksson, 1995a; Schaefer, 1997).

Because of the nature of the condition and the current limited extent of our knowledge about FM, it is important to elicit from patients their subjective descriptions of living with the condition. Based on the findings of qualitative research such as this study, nurses and others can better identify and understand the personal perspectives of patients with FM, and gain an improved understanding of the experiences of people living with this condition. This will thereby enable health care professionals to be more supportive, to plan better educational programs and coping strategies specifically tailored for such patients, and also provide emotional resources and coping strategies to their families. In addition, nurses have a role to play in bringing this knowledge to others and in communicating what patients with FM want others to know about their condition. This can help such patients feel understood, thus easing some of the burden of their illness (Asbring, 2001). When we gain insight into the perspectives of these persons, patients
will be better helped, and the health care community and the public as a whole will gain a better understanding of what it is like to live with FM.

Assumptions

The researcher assumed that participants in this study were able and willing to articulate their descriptions of living with fibromyalgia. It was also assumed that the participants provided honest accounts of the present experiences of living with FM, knowing that their anonymity and confidentiality were ensured. Finally, the researcher assumed that, although no two persons' experiences are the same, and that although experiences of living with the condition may differ according to differing management strategies, length of illness and other pre-existing chronic illnesses or injuries, common themes would emerge from participants' descriptions that would have implications for nursing.

Summary

Living with FM presents many challenges to the persons with the condition that necessitates the understanding of the phenomenon by both the health care community and the general public. This qualitative study addresses the gap in our knowledge of the individual's perspective on living with FM with the aim of improving our understanding of the condition and our ability to provide better care for such patients. This thesis is organized around five chapters. In chapter one, I introduce the problem, describe the research question and the assumptions underlying the research, and explain the nature and significance of the study. Chapter two contains a review of relevant literature related to FM, especially the literature dealing with the experiences of living with the condition. In chapter three, I outline the research methodology of the study, the selection criteria for
the participants, the recruitment process, the description of the participants, the method of
data collection and analysis, the steps taken to ensure the rigor, the ethical considerations
and the limitations of the study. Chapter four presents the study’s findings from the
interviews. Chapter five is the conclusion; here I discuss and analyse the findings of this
study, and discuss the implications for nursing practice, nursing education, and nursing
research.
CHAPTER TWO: LITERATURE REVIEW

Introduction

To locate the phenomenon of FM within the current body of knowledge, and to better understand how people with FM describe their experiences of living with the condition, the researcher conducted a broad review of the literature. This strategy is in keeping with the purpose of the interpretive descriptive method.

This chapter consists of five sections. In the first of these, I briefly address some of the etiologies and the treatment for FM. In the second section, I address the research that examines the effects of symptoms associated with FM. The literature includes some research concerning the quality of life of individuals affected by FM, which I review in the third section. In the fourth section, I examine studies that elicit individuals' perspectives of living with the condition. Finally, I summarize the available literature and its relevance to this study. In particular, I address in this final section the ways in which the literature illuminates the research question, “How do individuals describe the experience of living with fibromyalgia?”

Etiology and Treatment of Fibromyalgia

At present, the causes of fibromyalgia are still unknown, although there are several studies that have tried to establish its etiology (Aaron et al., 1997; Mengshoel & Haugen, 2001; Yunus, 1994). Some theories about the origin of FM include the following: a disorder in sensory processing in the central nervous system (Kosek et al., 1996; Sorensen et al., 1995, Sorensen et al., 1997); or a pain amplification disorder with localized area of reduced pain threshold (Bennett, 1995; Bennett, 1996b; Bernard et al., 2000b; Wolfe, 1994a). Another theory is that neurohormonal deregulation causes lower
than normal serotonin levels in patients with FM. Lower serotonin levels lead to a
decrease in non rapid eye movement (REM) sleep and an increase in somatic complaints.
The reduction in serotonin level also results in an increase of substance P, a
neurotransmitter that increases the sensory interpretation of pain (Okifuji & Ashburn,
2001; Richman, 1996; Seton & Polisson, 1995). Finally, viral infection has also been
suggested (Goldenberg, 1995; Slavkin, 1997).

There is a growing consensus in the literature that FM may arise from a complex
interaction of multiple factors (Adams & Sims, 1998; Bennett, 1995; Henderson, 2002;
Henriksson, 1994; Yunus, 1994). Several researchers have proposed the theory that FM is
genetic, but may require illness, stress, or injury to trigger its symptoms (Aaron et al.,
1997; Waylonis & Heck, 1992; Williamson, 1996). Several studies note that individuals
afflicted with FM have experienced a high incidence of trauma such as accidents,
ilnesses, injuries and surgeries, or emotional, physical, and sexual abuse before
developing the condition, and suggest that, although the exact role such events may play
in precipitating FM is not yet clear, these factors may serve as triggers for the onset of
FM symptoms (Aaron et al., 1997; Prince et al., 2000; Walen, Oliver, Groessl, Cronan &
Rodriguez, 2000). However, Hudson and Pope (as cited in Disney, 2000) attempt to
discredit the association between increased prevalence of FM and a history of childhood,
physical or sexual abuse. Specifically, they suggest that studies that make such a
connection contain sample bias and that, furthermore, there is a “tendency of suffering
individuals to seek some sort of explanation for their plight” (p.77).

Due to the absence of specific pathology underlying the symptoms of FM, other
researchers suggest that FM is a psychological disorder (Boissevain & McCain, 1991b;
Dunkin, 1997; Maurizio & Rogers, 1997; Okifuji, Tuck & Sherman, 2000) while others oppose this notion due to the inconclusive results from psychological tests (Anonymous 2000, Okifuji & Ashburn, 2001). Other studies suggest that should psychological trauma be involved, its role is to worsen the condition, rather than to act as its primary cause (Taylor, Trotter & Csuka, 1995; Walen et al., 2000).

There is an ongoing debate over whether depression precedes FM or accompanies it, for the condition may exist after depression is treated, just as depression may persist during treatment of FM (Bennett & McCain, 1995; Poteat, Bjerke, Johnston & Mairs, 1997). Other researchers (Bennett, 1995; Ekselius, Bengtsson & von Knorring, 1998; Merskey, 1993) have examined the relationships between psychological factors, psychiatric illness and FM, and have suggested that although the psychological effects of FM are related to the psychological effects of chronic pain and other symptoms of FM, they cannot be held responsible as the main cause of the condition. Bennett and McCain (1995) further suggest that the less depressed the individuals, the lower their levels of perceived pain; thus, they are better able to cope with their symptoms. Okifuji et al. (2000) argue that the psychological effects of FM are independent of the severity of pain or of other symptoms of FM, but are related to cognitive appraisals of the effects of symptoms on everyday life and functional abilities.

Additional studies have shown strong correlations between FM and somatization scores. Consequently, some researchers have concluded that the pain of FM—rather than a bio-medical condition—is a physical manifestation of various psychological conditions such as hypochondria, somatoform pain disorder, anxiety, psychogenic rheumatism, and other affective disorders (Aaron, Bradley & Alacron, 1996; Russell, 1995; Wolfe, 1994a;
Wolfe et al., 1995). Other research points to a theory that FM is not a product of somatization but, rather, may result from a pre-morbid psychological disorder; these studies show a higher incidence of depression and panic disorders in individuals with FM (Celiker, Borman, Oktem, Gokee-Kutsal & Basgoze, 1997; Creamer, 1999; McBeth, Macfarlane, Benjamin & Silman, 2001).

The proliferation of theories regarding the etiology of FM, and the doubt in some quarters about the existence of FM as a biomedical condition, indicate that there is a need for further research to resolve this important question. Yet, according to Smith (1998), some researchers have reported that “under the electron microscope severe damage and dissolution of myofilaments has been observed” (p. 663) in people with FM.

After many decades of research that has attempted to establish the etiology, pathogenesis, and diagnostic criteria of FM, many health care professionals have finally accepted the syndrome as a clinical entity with some specific classification criteria. The American College of Rheumatology has established the current diagnostic criteria for FM, which include the following: musculoskeletal pain on both sides of the body, above and below the waist, that lasts for a minimum of three months, and pain in at least 11 out of 18 specific points on applying digital pressure with a four kilogram per square centimeter force (Wolfe et al., 1990). According to these authors, the patient must report the palpation as “painful” as opposed to “tender” to confirm that the “tender point” conforms to this diagnostic criterion. The 18 sites that are typically painful upon gentle palpation, and that are used for diagnosis, are clustered around the neck, shoulders, chest, hips, knees, and elbows (see Appendix A). Along with the specific diagnostic criteria, other associated symptoms that help to establish a diagnosis of FM include fatigue, sleep
disturbances, chronic tension headaches, and cognitive or memory impairment (Bennett, 1996a, b; Boissevain & McCain, 1991a; Johnson et al., 1990; Vanderhaeghe, 2000; Wolfe et al., 1995).

Just as the cause for FM symptoms remains a matter of disagreement, so also is there no universally accepted treatment. Because many factors interact to cause symptoms, and symptoms vary from patient to patient, several authors (Adams & Sim, 1998; Estrada & Cook, 2000; Jones, 2001) suggest that a combination of various treatment options—including physical, psychological, and educational components—is more effective than are individual treatment modalities when dealing with the multidimensional nature of the syndrome. According to both Inanici and Yunus (2002) and Jones (2001), health care providers should individualize treatment modalities according to their patients’ symptoms and needs since no one particular treatment works effectively to satisfy the complex nature of the symptoms (Scudds & Li, 1997; Sturge-Jacobs, 2002). As participants in Sturge-Jacobs’ phenomenological study pointed out, the treatment modalities they used to manage their symptoms might work one day, but fail the next. This phenomenon greatly increases the continuing challenge of living with the condition.

The management of FM, then, typically involves an individually specific, multimodal approach that relieves symptoms through pharmacological, physical and psychological strategies, and educational components (Estrada & Cook, 2000; Anonymous, 2000; Hendersen, 2002; Slavkin, 1997). Such an approach offers a combination of treatment modalities to reduce pain, to help individuals increase sleep, and control the many other symptoms associated with the condition, and, as well, assist with psychological support and the teaching of a variety of skills aid in coping with the
condition (Bernard et al., 2000a; Poiro-Boisset, Esdaile & Fitzcharles, 1996; Rogers & Maurizio, 2000). To successfully manage symptoms in this way, a team approach, involving a variety of health professionals, is essential (Gremillon, 1998; Maurizio & Rogers, 1997; Turk et al., 1998).

Drug treatment is used to alleviate pain, minimize sleep disturbances, relax skeletal muscles, and relieve depression. The most commonly used pharmacological agents are low doses of tricyclic antidepressants such as Amitriptyline® to increase non-REM stage four sleep by increasing serotonin levels (Hendersen, 2002; Jones, 2001). Since tricyclics do not work well for some patients, the newer, selective serotonin reuptake inhibitor (SSRI) antidepressants such as Fluoxetine® (in combination with tricyclics to promote sleep and fight fatigue) have also been of some help for certain patients (Creamer, 1999; Maurizio & Rogers, 1997). As well, small doses of benzodiazepines may relieve muscles spasms (Creamer, 1999). Some more controversial pharmacological interventions, such as nonsteroidal anti-inflammatory drugs and steroids or local anesthetics such as lidocaine injected into tender points, have also been used (Adams & Sims, 1998; Slavdin, 1997; Sorensen et al., 1995). There is little evidence that the latter is effective since FM is associated with an absence of tissue inflammation (Henderson, 2002; Jones, 2001).

Since pharmacologic agents are not completely successful in managing symptoms, many patients with FM use non-pharmacologic treatment interventions (Alacron & Bradley 1998; Pioro-Boisset et al., 1996). Several researchers have suggested physiotherapy treatment with exercise as the primary intervention for FM (Nichols & Glenn, 1994; Schachter et al., 2003). Other management strategies include massage
therapy (Poteat et al., 1997), relaxation and meditation (Hendersen, 2002; Poteat et al., 1997), prayer and talking to friends, family, or professionals for social support (Bernard et al., 2000b; Nichols & Glenn, 1994; Ryan, 1995). Alternative treatment modalities such as biofeedback (Adams & Sim, 1998; Slavkin, 1997), heat therapy (Adams & Sim, 1998; Hendersen, 2002), acupuncture (Adams & Sim, 1998; Creamer, 1999; Jones, 2001), hypnotherapy (Creamer, 1999; Poteat et al., 1997), and cognitive behavioral therapy (Creamer, 1999; Littlejohn, 2001) help relieve the severity of FM symptoms for many patients for whom drug treatment has not worked (Creamer, 1999; Hendersen, 2002; Prince et al., 2000). Some reports state that a few individuals have used adverse coping strategies, such as alcohol, drugs, or suicide in response to FM’s relentless symptoms (Bernard et al., 2000b; Prince et al., 2000).

There are numerous studies that examine the effectiveness of the various treatment options (Adams & Sim, 1998; Buckelew et al., 1994; Buckelew et al., 1995; Gremillion, 1998; Jones, 2001; Karper, Hopewell & Hodge, 2001; King, Wessel, Bhambhani, 2001; Pioro-Boisset et al., 1996; Wassen, Beckman & Dudley, 2001). Rossy, Buckelew and Dorr (1999) in their meta-analysis of studies up to the year 1996 suggest that nonpharmacological treatments, such as exercise, patient education, and cognitive behavioral therapy, are more effective than drugs to reduce the symptoms of FM. The studies of Mengshoel, Komnaes and Forre (1992), and Mengshoel, Forseth, Haugen, Walle-Hanse and Forre (1995) look at the effectiveness of exercise and patient education for people with FM. The first study notes the effects of an exercise program on symptoms and physical functioning of these patients, and the second study notes the effects of an interdisciplinary patient education program. In 2001, Mengshoel and Haugen conducted a
follow-up quantitative study, in which only 33 out of the original 51 invited participants agreed to participate. Of these, 18 were in the exercise group and 15 were in the patient education group. These researchers examined the effects of an exercise program and an interdisciplinary patient education program on the symptoms, physical functioning, and nutritional status of these 33 patients after a six to eight year period. The follow-up study compares indicators used in the previous studies, such as pain intensity, fatigue severity, sleep problems, tender point count, nutritional and employment status; it also assesses cardiovascular capacity and restrictions on daily activities. This 2001 study notes that cardiovascular capacities of all 33 participants were within normal range, and that there were no differences in outcomes between those participants in the exercise program or the patient education group. The overall results showed no worsening of symptoms compared with data from the two previously mentioned studies, and a reduction of fatigue for the total sample. It is not clear from Mengshoel and Haugen’s 2001 report, however, whether the reduction of pain had led to the reduction in fatigue. This remains a query needing further research.

Mengshoel and Haugen’s findings echo those of other studies that suggest symptoms of FM remain relatively stable over time (Ledingham et al., 1993; Wolfe, Anderson & Harkness, 1997). Some limitations Mengshoel and Haugen (2001) report are (as I noted above) that (a) only 33 of the 51 invited participants took part in this study; and (b) participants were all recruited from the municipal primary health care services, and therefore may have been in better states of health than patients with FM from hospitals or from other areas. Mengshoel and Haugen (2001) also note an increase in the weight of their participants although there was no change in the dietary intake; these
researchers suggest that the weight gain might be age-related. The patients in both the exercise and the patient educational groups in the 2001 follow-up study reported that they used coping strategies such as reducing work time to allow for more rest, practicing relaxation techniques, using distraction techniques such as listening to music, reading, and staying physically active. The authors suggest that physical activity is important not only for symptom management but also for the general physical and mental health of patients with FM, just as it is for the general population. These findings are congruent with those of other studies which conclude that positive coping strategies help reduce the effects of symptoms in individuals with FM (Bennett et al., 1996; Burckhardt, Clark, O'Reilly & Bennett 1997).

The effects of a positive attitude on the part of patients with FM is a recurring theme in the literature. For instance, Bandura's (1986) theory postulates that when individuals believe in their ability to manage their symptoms and engage in positive health behaviors, their symptoms and physical activity also improve. Several researchers (Buckelew et al., 1994; Buckelew et al., 1995) also report that self-efficacy plays an important role in the success of treatment modalities. Buckelew et al. (1996) note that the higher the self-efficacy of individuals with FM, the greater the likelihood that these individuals would engage in physical functioning, and in the management of pain and other symptoms, thus improving their quality of life. Depression and patients' negative evaluations of their ability to control symptoms and reduce pain have an adverse effect on the efficacy of symptom management and quality of life. Equally, patients associate positive coping strategies and greater individual control with positive outcomes (Burckhardt et al., 1997; Culos-Reed & Brawley, 2000).
Effects of Symptoms Associated with Fibromyalgia

Numerous reports in the literature address the symptoms of FM and their effects on the patient’s life and activities of daily living (Gaston-Johansson, Gustafsson, Felldin & Sanne, 1990; Henriksson, 1994; Henriksson, 1995a, b; Henriksson & Burckhardt, 1996; Henriksson et al. 1992; Schaefer, 1995a). For example, Henriksson (1995a), in a qualitative study, explores how 40 women from the United States and Sweden perceived and described living with chronic muscular pain associated with FM and also examines the ways in which these women managed their daily lives, given the limitations imposed on them by the condition. The American women, recruited from a rheumatology clinic, were all Caucasians and were matched with Swedish women recruited from a pain and rheumatology clinic. The participants’ comments in the taped interviews fall into three main categories: encounters, consequences, and strategies. The women reported that following the onset of symptoms they encountered lengthy periods of investigation during which physicians struggled to elicit the causes of their symptoms. They also faced not only disbelief from their physicians when there was no clinical corroboration for the presence of disease but also mistrust from those they encountered in everyday life when there was a conflict between how unwell they felt and how well they looked. After diagnosis, these women were unable to continue their accustomed daily life routines, leisure activities and family life, and had to forego their roles of primary homemaker. These consequences meant that they had to modify their daily activities according to their changed abilities, adapt their attitudes to accept their new limitations, and develop new strategies to cope with their situations. These findings correspond to those of Burckhardt et al. (1993) who reported that many individuals with FM had to make changes in their
personal lives and careers. Such changes might affect income levels and result in additional stress on the patients and their families. In addition, marital relationships suffered strains due to the patients with FM's tiredness and their painful sensations resulting from physical contact with their partners (Chenhall, 1998).

Mannerkorpi et al. (1999) conducted a phenomenological study of 11 Swedish women with FM, aged 24-54, to learn how they perceived and coped with their symptoms in everyday life. These women had been affected by the condition for periods ranging from three to twenty years. They were asked to describe their symptoms and typical days from morning to evening. The women stated that some of the symptoms they experienced were widespread muscular pain, headache, migraine, stomach-ache and fatigue. The major theme to emerge from this study is that these individuals with FM perceive their situation according to one of four patterns: struggling, adapting, being in despair, and giving up. The study notes that one individual was struggling to cope with her symptoms, while three others were in the process of adapting and were able to mobilize their physical and psychological strength to fight their pain and fatigue and adjust to their restrictions. Another group of participants stated that they were in despair, for they could not keep up with their working life, household chores, leisure, and social activities. The remaining group of informants stated that they had given up: they were not able to control their symptoms, had to forego many of their usual daily activities, and spent most of their time resting in bed. Mannerkopí et al. noted that additional "longitudinal studies are needed to explore the extent to which these patterns...are stable or transitory phases" (p. 120). These authors also reported that individuals with FM were not a homogeneous group, a finding that might be explained by the individuals’ differing
perceptions of their symptoms and the particular coping strategies they employed. Mannerkorpi et al. also postulated that their findings might be explained by the differing lengths of time that participants had suffered with the condition, a manifestation of their patterns of coping, the presence of existing stresses, the availability of social support, or their differing levels of knowledge about the condition and its treatments. These comments correspond with other reports that persons with FM do indeed perceive a high degree of stress in their daily lives, and that depression is commonly present (Hanson & Gerber, 1990; Hudson & Pope, 1996; Yunus, 1994).

In 2002, Paulson et al. conducted a phenomenological hermeneutic interpretative study in Sweden to elicit the experiences of 14 men living with the pain of FM. The men in this study said they were living with a reluctant, uncooperative body that was constantly in pain, caused them fatigue and weakness, and left them with reduced energy to carry out the amount of activity they were used to achieving. The fluctuating nature of the pain made it difficult for them to make plans, to carry out jobs or chores, or engage in a social life—findings in agreement with other studies (Henriksson, 1995a; Soderberg et al., 1999). All these symptoms, with their accompanying limitations, brought feelings of anxiety and restlessness. The men reported that they did not feel fully understood by their families, friends, or others, even though these people believed they really were in pain. These study participants also reported that they strove to live as normally as they could with their limitations, to endure each day one at a time, and to maintain hope that, on some days, the pain would not get worse. A limitation of the Paulson et al. study was that the men involved were either all married or lived in partnership. Perhaps men who were
living alone might have described different experiences in terms of living with the pain of FM.

According to Corbin and Strauss (as cited in Paulson et al., 2002), chronic illness “…separates the person of the present from the person of the past, and affects or even shatters any images of self held for the future” (p.249). The men in the Paulson et al. study reported that they were confronted with a body that was different from the healthy body they formerly had, an observation corresponding to Gerschick and Miller’s (2001) report that the body is the central medium through which a person defines self. In contrast to the women in the Mannerkorpi et al. (1999) study, the men in the Paulson et al. study reported that they tended to conceal their pain and discomfort and felt that they tried not to complain about their symptoms, thus supporting the earlier observation of Paulson, Danielson and Norberg (1999) who noted the observations of some nurses and physicians that men with long-term pain tend to complain less about it than women. These researchers have proposed that perhaps a postulate of Newman (1997) might help to account for this. Newman, who studied masculinity and men’s bodies in the nursing context, suggested that men perceive a threat to, or loss of, their sense of masculinity if they express their feelings and fears. A quantitative study by Yunus, Inanici, Aldag and Mangold (2000) added a different perspective, showing that the men they studied had fewer symptoms, lower tender point tenderness, less fatigue, and less pain in general, than women had. These findings need further exploration.

After pain, fatigue is the second most common, bothersome symptom in patients with FM. The feeling of chronic fatigue differs from the temporary feelings of tiredness in healthy people that arises from excessive physical activity, a sedentary lifestyle, poor
nutrition, an increase in work or a lack of sleep; such normal tiredness is relieved by rest (Rodriguez, 2000). The fatigue of FM, in contrast, resembles CFS in that it is chronic in nature, lasts more than six months, and is unresolved or only partially resolved with sleep and rest. In FM, fatigue is experienced as a decrease in muscle endurance or a feeling of being totally drained of energy, the inability to maintain a normal routine, and an increase in the need for rest (Clauw, 1995). The severity of fatigue also varies each day and is usually connected to or aggravated by pain (Soderberg, Lundman & Norberg, 2002).

Soderberg et al. (2002) conducted a phenomenological study to elicit the meaning of fatigue and tiredness among 25 healthy women and 25 women with FM. These researchers conducted narrative interviews, transcribed audiotapes verbatim, and analyzed the text as a whole. Their aim was to identify patterns of meaning that would help the researchers gain an understanding of the phenomenon. While the healthy women reported tiredness as a natural, temporary feeling signifying the body’s need for recovery through rest, women with FM described their tiredness differently, and according to four major themes. Soderberg et al. identified these themes as: the “body as a burden,” as an “absent presence,” as an “interfering obstacle,” and a “hope of alleviation.” The study participants with FM related their sense of “the body as a burden” to the feeling of having an unusually heavy body that lacked the energy to move. These women reported that an “absent presence” was associated with a feeling of “walking in fog or being enveloped in wool”, a feeling of “being present but simultaneously being absent” (Soderberg et al., 2002, p.250). Participants with FM in this study noted that this was not the same fatigue that they would normally have felt going to bed in the evening. These women referred to the body as an “interfering obstacle” that lacked its former strength to maintain social
commitments and to perform ordinary tasks. They needed to make adjustments according to the restrictions imposed by the condition, prioritize activities, and save energy for the essential requirements of daily life only. The final theme that related to the fatigue of FM was women hoping to have an alleviation of their fatigue. The 2002 Soderberg et al. study revealed that healthy women recounted that tiredness was a temporary feeling after hard work that was relieved by rest. In contrast, women with FM, whose fatigue was overwhelming and unrelated to time of day or activity, could only hope, usually in vain, for relief with rest or sleep. This finding supports the description of fatigue by Cahill (1999) and Habel (2002).

The 2002 findings of Soderberg et al. were similar to those of the Tuck and Human 1998 study. This latter study explored the physical and emotional aspects of living with fatigue in 22 women aged 19-74, diagnosed with CFS. The women in this study reported that their fatigue disrupted their daily lives and drained them of the energy to dress, go to work, or meet people. They had to adjust their activities according to what their bodies allowed. In addition, the participants spoke of the contrasts in their lives before and after their illness. They reported that they felt their former ways of life had ended, the illness had caused them to lose everything they once enjoyed and worked for, and FM had caused them to give up things such as their job, business, and friends. Participants also reported feeling anxious, angry, frustrated, depressed, and hopeless as a part of living with CFS. Some talked about the support, trust, tolerance and understanding they received from those who understood how CFS affected their lives. Others said they were emotionally drained because they could not convince their family and friends of their illness. As tiredness and fatigue are commonly experienced by most people, the
participants of both the Soderberg et al. (2002) and Tuck and Human (1998) studies found that it was difficult for those who only experience normal tiredness to appreciate why those who suffer the unrelenting fatigue of FM or CFS are not able to assume their usual daily activities. Tuck and Human also discussed that the implications of their study for nurses included the need to be empathetic, understanding, and compassionate in providing care for patients living with chronic fatigue and to assist such patients to find ways to deal with their fatigue. These findings with respect to the fatigue of CFS are applicable to patients with FM, which also robs those it afflicts of the energy and motivation to take sufficient care of themselves, or to engage in social or other activities that interest them (Van Heck, 2002).

Quality of Life with Fibromyalgia

In addition to the foregoing studies that explored the effects of symptoms on the lives of patients with FM, various studies have examined the quality of life associated with FM. In this section I will first examine some studies that compared FM and rheumatoid arthritis (RA), then review other studies that examined quality of life in FM itself.

Some disorders in humans that are associated with musculoskeletal pain include RA, osteoarthritis, spondyloarthropathies, and lupus. In all these conditions, the pain that the individual perceives is proportional to the stimulus; however, the pain in FM differs in that it is not proportional to stimuli (Dessein, Shipton & Budd, 2000). RA is a chronic progressive disease with pain in the joints, stiffness, fatigue, and other systemic manifestations such as weight loss and anemia, whereas the pain of FM is in the soft tissues (Wolfe, 1999). Since FM is classified as a rheumatic condition (Gerecz-Simon,
Kean & Buchanan, 1991), the literature commonly compares patients with FM and RA, and physicians have to exclude RA before arriving at the diagnosis of FM (Adams & Sim, 1999; Slavkin, 1997).

Burckhardt, Clark and Bennett (1992) compared the pain perceptions in women with FM to women with RA and examined the relationships between depression, pain extent, and pain description in women with both conditions. These researchers administered the McGill Pain questionnaire (MPQ) (Melzack, 1975) to the individuals with FM and RA, and asked them to choose and circle from the given lists all the words that described their pain, and all areas of the bodies where they felt pain. Burckhardt et al. also administered the Arthritis Impact Measurement Scale (AIM), which contains subscales that measure anxiety and depression (Meenan, Gertman, Mason & Dunaif, 1982). This scale is a well-researched and validated instrument commonly used in rheumatic disease evaluation. Burckhardt et al. reported no significant differences between the FM and the RA groups in terms of age, marital status, education, or present pain intensity. Moreover, they found that disease duration did not explain any variance in pain. When these researchers compared FM and RA pain, they found that FM pain was similar to RA pain in that it was rhythmic, constrictive, thermal and dull in sensation. The pain in RA, they found, differed from that of FM in that RA pain was localized largely to the small joints and was rarely spasmodic, whereas the pain in FM was primarily reported to be a form of soft tissue pain affecting the fibrous connective tissue or muscles, tendons, and ligaments. The findings in the study suggest that the character and extent of pain in people with FM may be partially due to peripheral sensory components and not due to pain amplification as a consequence of depression. The perception of both the FM
and the RA groups was that their pain affected their quality of life because it triggered fatigue and reduced energy levels, functional activity, and mobility. Patients with FM usually rated their pain as more severe, more consistent, more emotionally and psychologically complex, and physiologically debilitating than the pain experienced by other chronic pain sufferers; similar findings are also reported by Boissevain and McCain (1991a, b). Burckhardt et al. suggested that because individuals with FM lack validation of their pain, they may reactively tend to view their symptoms as more severe; this in turn might have an impact on such patients who would then report a lower quality of life than patients with RA.

Burckhardt et al. (1993) performed a comparative analysis that explored differences in the quality of life of women with FM and women with RA, osteoarthritis, permanent ostomies, chronic obstructive lung disease, insulin dependent diabetes, and healthy controls. Burckhardt et al. used the AIM scale (Meenan et al., 1982). Items that measure the quality of life on the AIM include mobility, physical functioning, dexterity, social activity, household activity, activity of daily living, pain, depression, and anxiety. The higher the scores on the AIM, the higher the level of impairment caused by the disease. Age, disease duration, marital status, income, education, and health status were taken into consideration as possible covariates that might account for the differences in the quality of life scores among the groups. Quality of life was measured with the quality of life scale (QOLS), an instrument developed by Flanagan (1978). This scale is a fifteen item Likert-type scale with each item representing a variety of possible responses including affective components to which subjects could respond in order to give a total satisfaction score. Subjects were asked to indicate their level of satisfaction on a seven-
point scale with “one” meaning “highly dissatisfied”, and “seven” meaning “highly satisfied”. The scale measures perceived life satisfaction in areas such as health, work, recreation, learning, and relationships with family, friends, and significant others. This instrument has been tested and found to be reliable and valid for people with chronic illness (Burckhardt, Woods, Schultz & Ziebarth, 1989). Results from the Burckhardt et al. 1993 study showed that women with FM consistently scored lowest on the quality of life measure and had more negative feelings about and dissatisfactions with all aspects of their lives compared to other women. Burckhardt et al. could not explain the reasons for these findings but postulated that perhaps the many symptoms of FM—such as pain, fatigue and non-restorative sleep—affected these individuals in a far more complex way than had yet been identified.

These results with respect to quality of life with FM are similar to those of Gaston-Johansson et al. (1990) in their exploratory study that compared the feelings of people with FM and RA about pain, support from significant others, psychosomatic symptoms, activities of daily living, job satisfaction, and future expectations. Specifically, those with FM experienced more limitations in daily living, had stronger negative feelings about themselves, experienced low self-esteem, self-worth, and self-confidence, and felt more pessimistic about their future than did patients with RA. Gaston-Johansson et al. suggested that the findings of their study have implications for health care providers in terms of their helping patients to adopt a more positive evaluation of their illness in order to be able to better manage their condition and live a normal life.

Henriksson et al. (1992) conducted a study in 1984 to investigate how the long-term effects of FM influenced the ability of Swedish patients to manage their everyday
lives. Five years later, Henriksson (1994) did a descriptive correlational follow-up study with 56 of the original 58 patients in order to determine the long-terms effects of FM in their lives. A mailed set of questions was common to both studies and the Bergner, Bobitt, Carter and Gilson (1981) global health assessment instrument, called the sickness impact profile (SIP), was added to the latter study in order to elicit the patients' perceptions of their symptoms and the consequences of these symptoms in their lives. The questionnaire consisted of questions about social background, FM symptoms and health-related issues, employment situation, home maintenance, leisure, and social relations. The SIP instrument contained 136 items grouped into twelve categories and the respondents indicated only those statements that described any of their present behaviors that they perceived as consequences of their disease. The twelve categories were ambulation, mobility, body care and movement, social interaction, communication, alertness behavior, emotional behavior, sleep and rest, eating, working, home management, recreation, and pastimes. The results of Henriksson's study indicated that FM was a non-remitting disease, with fifty percent of the patients reporting that the symptoms of pain, fatigue and sleep problems had increased, thirty to forty percent reporting no change, and fewer than twenty percent reporting improvements. As compared to the results from the earlier study, participants in the latter study reported that they found motor tasks easier to manage. Henriksson speculated that this result was due either to a functional improvement or to the patients having adapted physically and psychologically as a result of growth and maturation brought about by living with the disease over time (Henriksson, 1994; Schaefer, 1997). The limitation of the Henriksson
1994 study was that it was based on the subjective reporting of the patients, and some recall bias might have occurred over a five-year period.

In 1996, Henriksson and Burckhardt investigated how women with FM in the United States (US) or Sweden reported how FM affected their daily life activities. Twenty Caucasian U.S. female patients from a rheumatology clinic were compared to 20 Swedish patients who were recruited from a pain or rheumatology clinic. Both groups of patients were matched for age, sex and duration of disease. Data were collected using questionnaires, diaries and interviews. The fibromyalgia impact questionnaire (FIQ), (Burckhardt, Clark & Bennett, 1991), commonly used in FM research, with a Cronbach’s alpha of 0.8, was used to assess the health status of women with FM. The FIQ contained components on physical, psychological, social and global well-being. The QOLS (Flanagan, 1978; Burckhardt et al., 1989) which had been validated for use in Sweden and had been reported to have good reliability, good content validity and discriminant validity (Burckhardt et al., 1989) was used to measure quality of life. The patients were asked to mark their responses on the questionnaire and the QOLS. The patients completed a two-day structured diary indicating their pain and activity level prior to their interview. A semi-structured interview based on the Occupational Case Analysis Interview and Rating Scale (OCAIRS), (Kaplan & Kielhofner, 1989), was used to examine the influence of physical and social environmental factors on the impact of the disease as it affected the participants’ performance in their daily lives. The OCAIRS had a Cronbach’s alpha of 0.91 indicating good internal consistency reliability.

Henriksson and Burckhardt (1996) reported that there were no significant differences between the two groups in their overall use of time allocated to personal care,
home maintenance, work, leisure, night rest and rest during the day. Despite this finding, the results of the study also revealed that the symptoms had a greater impact on the patients of the US group than the Swedish group. The former group reported that they had less time for home maintenance, had more stress, felt more exhausted and were more dissatisfied with all aspects of their lives. Henriksson and Burckhardt stated that this difference could not be explained by either the severity of the symptoms or the personal individual characteristics of the subjects. Instead, they attributed the difference in symptom perception to differing socioeconomic situations and different health care systems. In Sweden, people with FM were entitled to receive disability benefits to cover their loss of income if they were totally or partly unable to work. On the other hand, patients with FM in the US usually encountered difficulties in claiming disability benefits. The majority of the women in the Swedish group had reduced their working hours, and were less exhausted during their leisure and daily activities, while the women in the US group worked full time and were more exhausted. Henriksson and Burckhardt suggested that different cultural settings and health care systems might influence how the impact of FM was experienced. These investigators further suggested that it was important to acknowledge the influence of each patient’s unique life situation in terms of their living with FM.

In 1993, Ledingham et al. carried out a descriptive correlational study on 72 patients with FM in order to investigate health outcomes in terms of symptoms, functional impact, and development of other diseases in patients. The results showed that the more severe the symptoms, the greater the functional disability and the levels of anxiety and depression, a result that was also supported by Kurtze, Gundersen and
Svebak (1998). It was not possible to tell from these studies, however, whether psychological problems were causal factors in FM or whether these problems influenced the individuals' ability to cope with the outcomes of the condition. Robbins, Kirmayer and Kapusta (as cited in Kurtze et al., 2001), suggested that "...feelings of vulnerability and apprehension about having an illness of unknown origin may contribute to FMS sufferers's activity limitations, inability to sustain a work effort, and varied somatic distress" (p.50).

Kaplan, Schmidt and Cronan (2000) conducted a study using the Kaplan, Bush and Berry (1975) quality of well-being (QWB) scale to assess the health and well-being of 594 participants with FM. The QWB scale was used because it allows researchers to examine and correlate aspects of physical functioning such as mobility, physical activity, and social activity, with pain, stiffness, anxiety, sleep-quality, and depression. This scale has a reliability greater than 0.90 and has been used to evaluate therapeutic interventions for a wide range of medical and surgical conditions. The scale contains a variety of items within which the subjects indicate their most undesirable symptom or problem, with a level of wellness ranging from zero (total dysfunction) to one (optimal asymptomatic functioning). The results showed that patients with FM had QWB scores lower than the scores reported by patients with other chronic diseases such as end-stage cancer, human immunodeficiency virus disease and chronic obstructive pulmonary disease. This 2000 study by Kaplan et al. was limited in that the participants were all volunteers from one private health organization in one metropolitan area, and so it was not possible to generalize from these findings; longitudinal studies, as these researchers recommended, could follow up the changes in quality of life over time. Despite these limitations, the
results corroborate the findings of other quantitative studies which showed that patients with FM rate their quality of life lower after diagnosis because of the adverse impact of FM on individuals’ personal relationships, careers, mental health and social support systems (Bernard et al., 2000a, b; Clauw, 1995; Wolfe et al., 1995).

Some research on FM has suggested that certain psychosocial variables—for example, a sense of coherence and identity (Asbring, 2001; Soderberg, Lundman & Norberg, 1997), the ability to deal with stress (Dailey, Bishop, Russell & Fletcher, 1990; Uveges et al., 1990), and the evaluation of one’s ability to manage the condition (Burckhardt et al., 1997, Gaston-Johansson et al., 1990)—may affect the ways individuals affected with FM perceive their symptoms and their ability to cope with them. Burckhardt et al. also found that depression and a negative evaluation of their ability to control pain had an impact on the perceptions of people with FM regarding their control over symptoms; accordingly, they perceived that their quality of life was poorer.

Soderberg et al. (1997) found that women with FM who scored high on the Antonovksy (1987) “sense of coherence” scale possessed a greater feeling of confidence in terms of having the resources to meet the demands derived from their internal and external stimuli. These women also perceived a greater sense of well-being despite more severe symptoms than women who scored lower on the “sense of coherence” scale. The Gustafsson and Gaston-Johansson’s (1996) results also support this finding. These researchers noted that people with FM who perceived that they did not have control over their situation perceived less “well-being” and needed additional nursing support. Lazarus and Folkman (1984) suggested that both problem-oriented and emotion-oriented coping strategies can help reduce vulnerability to stress and the severity of the burden of
illness. Thus, there are immediate implications for nurses in the above-mentioned findings of Asbring, (2001), Burckhardt et al. (1993), Burckhardt et al. (1997), Dailey et al. (1990), Gaston-Johansson et al (1990), Gustafsson and Gaston-Johansson (1996) and Soderberg et al. (1997). All these authors suggest that health care professionals, by promoting a variety of coping strategies, might be able to help affected patients overcome their feelings of helplessness, might regain belief in their ability to exert control of their symptoms, and thereby might better be able to deal with their condition.

Most of the foregoing studies measured the quality of life for individuals with FM by means of quantitative approaches such as using scales and instruments to measure symptoms, health status, physical functioning, and capacity for work. In addition, however, according to Nord, Arsenen, Menzel and Pinto (as cited in Van Heck, 2002), it is important to address quality of life in the way the ill person perceives it. Such a viewpoint would encompass individuals' "...perspectives on life, roles, relationships and experiences...their overall feeling of well-being and their view of the desirability of the life they are living" (p. 20). It is important, therefore, using qualitative research methods to elicit the subjective attitudes and perceptions of these individuals about their health, well-being and quality of life in order to add to the understanding of FM. In fact, many more qualitative research studies would be a useful addition to the literature.

Living with Fibromyalgia

Only a few recent qualitative studies address the experience of living with FM. Some qualitative studies also compare FM with CFS. Soderberg et al. (1999) used the phenomenological-hermeneutic method to elicit the experiences of 14 women living with FM. A purposive sample was obtained from a rheumatological clinic in northern Sweden.
These women, aged 35-50 years, had had FM for six months to six years. Structural analysis of the narrative interviews revealed three major themes: loss of freedom, threat to integrity, and struggle to achieve understanding and relief. Participants reported that their loss of freedom was related to the constant experience of pain, fatigue, and various bodily sensations. They described their pain as generally widespread and either pulsating, vibrating, shooting, or aching in nature. The location of the pain also varies, they reported: it could be in the knees, hips, feet, and the back of the head. They described the fatigue of FM as all-pervasive; it deprived them of the energy they needed to carry out activities. These findings are similar to those of other researchers (Cahill, 1999; Habel, 2002; Lundman & Norberg, 2002) who described this fatigue as unrelated to activity level and not relieved by adequate rest or sleep. The participants in the Soderberg et al. study also mentioned that another aspect of this first theme was the constant presence of symptoms that had impacted their physical, familial, social and work lives.

Participants in the 1999 Soderberg et al. study reported that the presence of FM in their lives meant that their integrity was threatened. This second theme was one that stemmed from a significant characteristic of the illness: health care professionals, friends and families did not consider the illness credible due to the invisible nature of the condition. These women experienced negative attitudes and a general lack of knowledge about their condition from both members of the public and health care professionals.

The third theme from the Soderberg et al. study was the struggle to achieve understanding and relief. It had four aspects to it. Women in the study described their search for explanation of their illness, their need to seek relief when a diagnosis was achieved, their use of various treatment strategies to alleviate their symptoms, and their
need to plan their lives according to the exigencies of their illness. Toombs (as cited in Soderberg et al., 1999) suggests that “when people are healthy, the body is taken for granted, but when someone falls ill, the body can no longer be taken for granted; there is a deep sense of the loss of total bodily integrity” (p. 583). Lanara (as cited in Soderberg et al.) contends that dignity has dimensions of credibility, status, position, appearance and reputation, and that “man’s dignity is connected with the absolute value of being a human being” (p. 583). Such a notion—that the disruptive power of such threats to one’s bodily integrity contributes to a sense of loss and despair—connects the three themes that the Soderberg et al. study revealed.

Other qualitative research includes the Soderberg and Lundman (2001) study, in which the researchers interviewed 25 women living with FM in northern Sweden. Twenty women were recruited from a rehabilitation centre while the other five were recruited from a rheumatological clinic. Their ages ranged from 35 to 60, they had experienced symptoms for about four to 25 years and the time that had elapsed since their diagnosis had been made was from one month to ten years. Thematic content analysis of the data revealed that the women had to make transitions in their patterns of daily life, family life, social life and working life due to the debilitating effects of the symptoms associated with their condition. Congruent with the findings of other researchers of FM (Hallberg & Carlsson, 2000; Hughes, 1999); the women in Soderberg and Lundman’s study stated that their lives were altered and guided by the disease and that they had to learn to live with the changes brought about by it. Some also expressed anger and frustration because FM prevented them from doing what they wished, and they had to plan their days according to their strengths and limitations. These findings correspond
with those of previous research (Henriksson 1994, 1995a,b; Soderberg et al., 1999), all of which indicated the life transitions people with FM encountered. In their family lives, the women in Soderberg and Lundman’s 2001 study had assumed a more passive role, relinquishing many of their past household responsibilities. This meant that they needed more help from family members who, seeing their relatives’ healthy appearances, might not fully understand their situation. These women reported that their relationships with their husbands were also affected by the illness. These findings were in accordance with other research findings that have determined that when a family member falls ill, the entire family is affected (Chenhall, 1998; Lubkin & Larsen, 2002). Soderberg and Lundman also found that in their working lives, these women had to switch their jobs from full time to part time, or switch to pension or disability due to their lack of energy to work. Their pain, fatigue and lack of energy also forced these women to make adjustments in their social lives. Their friends could not understand why they were not going shopping, going out to dinner, or doing many of the other things they had enjoyed before, and the sufferers gradually became alienated from their friends. Though these women did not explicitly talk about the lack of control in relation to their illness, they talked about learning to adjust to a disrupted life. These findings supported those of Register (as cited in Soderberg & Lundman, 2001), who noted that accepting one’s chronic condition “is taking responsibility for constructing a life in the spaces between the moments of dysfunction and adopting habits that will keep them to a minimum of intensity and frequency” (p. 628). A theme that was prominently discussed by Soderberg and Lundman in their study was the theme of invisibility associated with FM. The women in this study stated that “it is like living in two worlds simultaneously, the world
of the sick and the world of the healthy” (Soderberg & Lundman, 2001, p. 617) due to the “invisible alteration” from the disease.

Invisible alterations have consequences for people living with FM. One of these is the experience of being stigmatized. According to Anderson and Bury (1988) such a stigma is “the result of interaction between individual and community values through which the individual feels devalued and subject to negative stereotyping” (p. 178). Goffman (1963) has observed that stigma can be divided into two classifications: discredited or discreditable. According to Lubkin and Larsen (2002) a discredited condition is “one with visible cues” whereas a discreditable condition is one where the individuals do not possess “obvious clues to the defect.” (p. 57). Since FM is a condition in which the sufferers do not have obvious visible disabilities, this stigmatization of persons with FM is of the “discreditable” type, and is a frequent occurrence (Asbring & Narvanen, 2002; Strok, 1998; Vanderhaeghe, 2000).

In 2002, Asbring and Narvanen studied the issue of stigmatization as it occurs in the experience of living with CFS and FM. The researchers interviewed 12 women with CFS and 13 women with FM in two Swedish hospitals. These women reported similar experiences: there is an enacted stigma attached to the invisible nature of both conditions, a finding echoed by others, including Sturge-Jacobs (2002), who found that stigmatization was also experienced by Canadian patients with FM. The Swedish and Canadian women in both these studies reported that others questioned their work ethic, and that they also had problems trying to get disability insurance benefits from their insurance companies. That is, since there were no outward signs of the illness (although it affected their ability to work) others tended to perceive them as malingerers. The other
stigmatization these women reported was that their physicians, unable to find a physical cause for their illness, began immediately to wonder if the origin of the condition was psychological. The women in Asbring and Narvanen's 2002 study reduced the risks of stigmatization by withdrawing from others who were reacting negatively toward them, by concealing their diagnosis from others, or by divulging their illness to only a few selected people. These findings correspond to Goffman's (1963) and Joachim and Acorn's (2000a, b) discussions of stigma, something these authors found commonly associated with a chronic condition. According to Joachim and Acorn, if the signs of stigma are invisible to others, the individuals are discreditable though not yet discredited. In FM, the condition is invisible and patients state that they often feel worse than they look. People with invisible conditions may choose to disclose their condition, a decision that may either lead to being discredited or may lead to increased support from understanding individuals. On the other hand, sufferers of FM may choose to pass as being normal by deliberately concealing the condition that is invisible to others. Lastly, individuals may choose to engage in protective disclosure, controlling how, what, when and to whom they talk about their condition. This choice has implications for nurses trying to understand the experiences of the individuals in order to help them employ good, and individually appropriate, coping strategies to deal with their situation.

Schaefer (1995a) did a qualitative study of 36 women with FM using a combination of grounded theory and feminist methods. The sample was obtained by the snowball method through community programs for CFS and other related disorders such as FM. These women described living with FM as struggling to maintain balance. Their experience involved five categories: "recalling perceived normality" (reflecting on life
before the illness), “searching for a diagnosis,” “finding out” more about the illness, “moving on” by transcending the illness, and “relinquishing the struggle” with the illness. The participants in Schaefer's study reflected on their lives before the illness, their long search for a diagnosis, their struggle to maintain a balance (which continued after the diagnosis was confirmed) as the women attempted to find out how to manage their symptoms. Schaefer stated that some women were able to develop new capabilities and transcend the difficulties associated with their illness; these women were able to move on with their illness and relegate it to the “backdrop” of their lives. Other women expressed depression, anger, and grief as they constantly struggled to maintain balance in their lives. Some gave up as their conditions became out of their control, while others lived on with their struggles, dependent on the support of families and others. In another study in 1997, Schaefer analyzed the daily diaries of eight women with FM. The major themes gathered from these diaries recounted the mental and physical components of pain that added stress to the women's daily life. These women also reported that they had to live their lives according to the patterns of their symptoms.

Asbring (2001) used a grounded theory approach to interview 25 women in Sweden—12 with CFS and 13 with FM—to elicit their concepts of their identities after biographical disruption associated with their illness. Bury (as cited in Asbring, 2001) referred to biographical disruption as a point at which “the structures in daily life become disjointed” (p. 324). The women in Asbring's study expressed grief over the loss of their previous identities because of their illness, particularly in relation to work, social life, and relationships with their partners. Asbring described their biographical disruptions as partial rather than total, necessitating different degrees of identity transformation. Many
of these women also experienced illness gains as they came to terms with their new identities. Asbring stated that biographical disruption and illness experience existed in a paradox consisting of both losses and gains and it was important that health professionals could acknowledge this as an important part of the illness experience. Asbring’s observations seem to correspond to Paterson’s (2001b) finding that some individuals with chronic condition may take their illness experience positively as an opportunity for transformation. These findings were in contrast to the belief underlying the more usual approach of professionals, that is, to endeavor to help persons to accept the limitations associated with chronic illnesses. Reed (1999) also raised the question of whether the individuals’ views of their lives as they continue living with FM change over time due to growth and maturation.

Sturge-Jacobs (2002) conducted a phenomenological study to elicit the experience of living with FM of nine women from Newfoundland aged 29 to 56 who had the condition for more than a year. Although these women were similar in marital status and nationality, they differed in age, educational level, personality, level of social involvement, mental capacity, lifestyle, health status, and the number of years living with FM. Some of the findings that emerged from the Sturge-Jacobs data were: the constant experience of symptoms such as pain, fatigue and sleep disturbance; the unpredictability and fluctuating nature of the symptoms; the power of naming—seeking a diagnosis; the struggle to live within the boundaries of the illness and attempts to maintain a normal life. These findings of Sturge-Jacobs were similar to the findings of other studies (Henriksson, 1995a, b; Schaefer, 1995a): specifically: that the symptoms of FM are varying and fluctuating in nature so typically people with FM need to visit various medical
professionals and undergo a number of medical procedures to get a diagnosis. All the women in Sturge-Jacobs' study found that their experiences of pain were discounted by their health care professionals. This trivialization of their experience caused them further frustration and anguish, but enhanced the relief they felt when a diagnosis was made. In accord with other studies (Henriksson, 1995 a, b; Soderberg & Norberg, 1995) the participants of Sturge-Jacobs' study found that the constant, unpredictable fluctuating nature of the symptoms made it a challenge to cope with the condition and also caused these women to have to relinquish some of their former preoccupations. They could no longer engage fully in social, marital, employment, parenting, or homemaker roles—findings that were in agreement with previous research (Henriksson 1994, 1995 a,b; Soderberg et al., 1999; Soderberg & Norberg, 1995). The difficulty of trying to fall asleep while in pain and waking up after sleeping for only a few hours impaired the attentiveness, memory, problem-solving, and other cognitive abilities of the individuals. Some women in the Sturge-Jacobs study spoke positively of their pain (as did participants in the Asbring, 2001; Henriksson, 1995a, and Henriksson, 1995b studies), and explained that it protected them from engaging in too much daily activity. The women stated that they had to live within the boundaries of their condition by prioritizing and pacing their daily activities to allow time for rest and relaxation. Congruent with Soderberg and Lundman, (2001) and Soderberg et al. (1997), most participants in the Sturge-Jacobs study expressed pain as a negative factor that hindered their usual activities and caused misery and suffering. Most of these women also expressed the desire to live a normal life in spite of the limitations imposed by their conditions.
Some of the themes reported in Sturge-Jacobs (2002) were similar to those found by Cudney, Butler, Weinert and Sullivan (2002). These researchers asked ten rural women in Montana to participate in a telecommunication self-help discussion group to share their concerns, struggles and the advice they could offer or receive from each other in their experiences of dealing with FM. The major themes that emerged from these data were struggles with pain, fatigue, depression, sleep disturbances, and the use of self-pacing and other creative strategies to persevere with the condition. These women, who lived in remote rural areas, stated that it was important to have a support system in order to deal with their feelings of isolation from services.

Hughes (1999) used the narrative inquiry approach to explore the life stories of ten women with FM aged 34 to 55. These women were all Caucasian with different educational and social backgrounds. Common or divergent patterns across participants' stories were identified. Some of the common patterns were childhood memories related to the pain and aches of growing joints and muscles, emotional and sexual abuse, family illness and tensions and early childhood responsibilities. These findings were congruent with earlier research postulating that childhood growing pains might be an indication of a genetic predisposition toward developing FM in later life (Starlanyl & Copeland, 1996). As stated earlier, a few studies have suggested a high prevalence of trauma before the onset of FM symptoms, though the exact role of these events in the precipitation of FM is still not known (Walens et al., 2000). Other informants in Hughes' (1999) study had family members who had mood disorders, a finding supporting an observations reported by Creamer (1999) and Okifuji, Turk and Sherman (2000) who noted that there was a high rate of mood disorder in the families of individuals before their diagnosis of FM.
Additional themes that came out of the Hughes (1999) study were consistent with those that had been reported in the literature earlier: the need for frequent visits to physicians before getting a diagnosis, the experience of relief when a diagnosis was received, the effects of the symptoms of FM on physical, familial, social, and working lives. In particular, the seven women in Hughes' study who had to forego employment reported that it took a long time for them to receive disability benefits because the courts did not recognize FM as a clinical entity. Two women reported that they were able to negotiate flexible work hours with their employers, who exhibited understanding of their condition. Like the women in Asbring's (2001) study, some women in Hughes' study reported that the illness had transformed them into stronger people, and caused them to develop new patterns of living with the disease, abetting a connection with spirituality to help build a strong faith to transcend the illness. This finding was congruent with other researchers who have stated that chronic illnesses may often bring positive changes in the identity of sufferers (Morse, 1997; Royer 1995; Schaefer 1995b). The women in Hughes' study, similar to the findings of Sturge-Jacobs (2002) noted that their participants found being aware of their symptom patterns helped them gain some control over their illness. Some women made an effort to consider their own physical and emotional well-being as their main priority in order to deal with their continuing struggle to gain control over their situation. Others, however, depended on the support of families and friends to achieve the same end. These narratives show that each woman's illness has its own unique pattern.

Summary

This literature review has revealed that most studies pertaining to FM are quantitative in nature. Such studies examined the etiologies of FM, the efficacy of
symptom management and treatment modalities, and the effects of symptoms such as pain and fatigue on the qualities of life in these individuals. However, by their nature, quantitative studies do not address the ways in which individuals with FM perceive their daily lives. Several researchers compared various aspects of FM with RA, because patients with both conditions suffer from chronic pain. Although these conditions have much in common, RA has a known etiology and a slightly different symptom list, whereas the cause of FM is still unknown – and significantly, the condition is often discounted. Additional, qualitative studies that examine FM specifically, or investigate the differences between FM and other similar conditions, would help to address some of the gaps in our knowledge.

Other researchers examined the effects of symptoms and treatment modalities associated with FM and how individuals perceived their symptoms. These approaches, however, only addressed one aspect of the experience of people living with FM. They did not elicit the multifaceted consequences involved in living with FM, as this study does. As with any chronic health issue, living with FM involves a process of learning more about the pattern and progression of the disease in one’s own case, the need to make sense of the FM experience, and the need to develop a workable approach toward living with the condition as a whole, an approach encompassing body, mind and spirit in its social context – as Thorne (1993) suggests in her study of chronic illness.

The qualitative studies I have reviewed provided a valid body of research regarding the physical, emotional, work and social consequences of FM on individuals’ lives. Most of the studies of FM have been conducted in Sweden, and some in the United States. Participants in all these studies lived in different cultural and societal settings with
different insurance systems and working conditions than those in Canada. Since the
general outlook of people’s lives is shaped to a large degree by the surrounding socio-
cultural environment, these differing environments might influence how these individuals
described their experiences living with their condition (Disney, 2000; Hughes, 2002). The
Sturge-Jacobs (2002) study, based on the phenomenological method, was done in Canada
but its Newfoundland setting may not be entirely representative of the experiences of
people with FM living in British Columbia, or other parts of Canada, since the two
provinces are socio-culturally distinct in many ways, and have different disability
benefits, and different services covered by the Medical Services Plan.

To date, I have found only three qualitative studies that examined the experiences
of living with FM: one used the phenomenological approach based upon the
philosophical traditions of other disciplines; the second study used the grounded theory
approach; the third study used the narrative inquiry method to reconstruct the individual
life stories of a sample of women with the condition. To date, I have found no study that
has used the interpretive descriptive approach to address nursing’s theoretical and
practical questions regarding the essence of what it is like to live with FM in a particular
context. Thus, this study addresses a gap in the literature that will add to some additional
implications for nursing patients with FM.

The main themes that emerged from the literature review and that pertain to living
with FM were the constant, varying and unpredictable nature of the symptoms; the need
to legitimatize the illness to others; the stigma associated with the invisibility of the
condition and the discrepancy between how well patients looked and how they actually
felt; the effects of the symptoms on their personal lives; and the strategies they used to
manage FM. My review of the literature failed to discover any nursing studies that have used an interpretive descriptive approach, the method used in this study, to examine the perceptions of people who live with FM. Such an approach is a valuable one and will help provide an increased understanding of how people with FM live and manage their condition within the context of their lives.
CHAPTER THREE: METHODOLOGY

This chapter presents the research method that I used in this study, the selection criteria for the participants, the recruitment process I employed, and a description of the participants. In addition, it addresses the data collection and the analysis methods, the strategies I used to ensure rigor in the research process, and the means I employed to protect the rights of the participants. Finally, I note some limitations of the study.

Research Method

The design selected for a study should be directed by the research question. Since the qualitative method seeks to understand a phenomenon from the interviewee’s perspective (Payne, 1999), it is the most appropriate method when little is known about a phenomenon and further exploration is needed (Creswell, 1998). In recent years, researchers have changed their approach to studying chronic illness from the outsider perspective, often preferring to explore the insider perspective (Schneider & Conrad, 1980, 1983; Thorne & Paterson, 1998, 2000) through qualitative research.

Other qualitative methods, such as grounded theory or phenomenology, could be used to answer the research question guiding this study. However, since these methods are based upon the philosophical traditions of other disciplines, they may not adequately answer all of nursing’s theoretical and practical questions regarding the essence of an experience in a particular context (Thorne, Reimer Kirkham & Macdonald-Emes, 1997). Thus, I selected the interpretive descriptive method (Thorne et al., 1997), an approach rooted in the philosophical tradition of nursing, to address the research question in this study: “How do individuals describe their experiences of living with fibromyalgia?”
The interpretive descriptive method allowed the researcher to elicit multiple descriptions of the shared elements of living with FM while acknowledging the individual "...constructed and contextual nature of much of the health-illness experience" (Thorne et al., 1997, p. 172). The analytical framework that guided this inquiry was derived from a critical analysis of the existing body of knowledge that speaks to the experience of living with FM. This body of literature was then compared with the findings of the current study in an attempt to organize the knowledge that captured the essence of living with the phenomenon within the context of participants' general lives. Using this approach I hope to provide an analysis that will enable health care professionals to arrive at a better understanding of what it is like to live with FM from the individuals' perspectives.

Selection Criteria for the Participants

In the interpretive descriptive design, the persons living the experience are considered the most appropriate sample to be drawn from in order to provide reliable and accurate information of the phenomenon under investigation. Participants for this study were selected by purposive theoretical sampling as proposed by Thorne et al. (1997). This sampling method was based on the abilities and willingness of the participants to describe their experiences. Once distinct themes were identified and unique and common aspects of the experiences were understood, the Glaser and Strauss (1967) approach to theoretical sampling was used to recruit additional participants for further clarification and illumination of the phenomenon until data saturation was achieved. This procedure allowed for maximum variation in the sampling to achieve a wide range of abstract levels of conceptualization around the experience of living with fibromyalgia (Lincoln & Guba,
A sample of eight participants was recruited for this study, a figure comparable with other studies conducted with people with FM. Morse (1991) recommends evaluating the adequacy and quality of the data to discover when sampling is sufficient. Recruitment of the participants in this study continued until data saturation was achieved, the evidence for which was the recurrence of conceptual categories, and a lack of new themes emerging from the data.

The criteria that were established for the study were that the participants had to be diagnosed with FM, capable of giving informed consent, living in the Lower Mainland of British Columbia, and fluent in both written and oral English. All participants met these criteria. The third of these criteria enabled the researcher to have easy access to the participants for initial and follow-up interviews, and the fourth criterion was selected so that the researcher did not need interpreters for the interview process.

Recruitment Process

The researcher took several steps to gain access to the participants for the study. Upon receiving the necessary ethical approval from the University of British Columbia Behavioral Sciences Ethical Screening Committee, the researcher requested assistance in recruiting participants from several sources who have frequent contact with people with FM: two rheumatologists, the British Columbia Fibromyalgia Society (BCFS) and a key informant. A letter of introduction describing the study and requesting assistance was given to these sources (Appendices B1, 2, 3). This method relied upon the key informant and the receptionists at the rheumatologists' offices to give the participant information letters (Appendix C) to individuals who met the selection criteria. Interested individuals contacted the researcher to gain further knowledge of the study. At that initial contact,
further explanation of the study was offered and arrangements were made for first
interviews. At the time of the first interview, the researcher reviewed the purpose and
nature of the study and allowed opportunity for questions. The informed consent
(Appendix D) was obtained from those who agreed to participate and a copy of the
participant information letter and informed consent were given to each participant for
their records.

For reasons unknown to this researcher, none of the eight persons who
participated in this study heard of it through the rheumatologists or the BCFS. Instead, all
of them heard about the study from the key informant, through some of the researcher’s
social contacts who were aware of the research, or by reading a UBC School of Nursing
newsletter that featured the research being conducted—an unforeseen report that came
about midway through the project.

Description of the Participants

The eight participants in this study varied in age. One participant was in her early
thirties, one in her late seventies and the others were in their fifties. All the participants
were Caucasians. Seven of the participants were female and one was male. The duration
of their experiences living with fibromyalgia ranged from eighteen months to thirteen
years. All of the informants lived in the Lower Mainland of British Columbia. Four
participants noted that they had sustained whiplash injuries or other injuries in car
accidents prior to the onset of FM. Two participants reported that they had histories of
emotional or physical abuse in their earlier lives.

Most participants described their FM as stable during the time of the interview,
except for two participants who described their FM as being in the "flare-up" stage. Three
participants were divorced and were single parents. One of these three stated that the failure of her marriage was related to FM whereas the divorces of the other two participants happened prior to their diagnosis. The other four participants were married. Three were living with their spouses and children. The fourth participant lived with her spouse and had children who lived away from home. One participant was single.

The financial circumstances of the participants also varied. One participant was retired with adequate pension income for daily living; six participants were not able to work and were on disability benefits due to their FM. Only one participant was able to engage in occasional casual work, something made possible by her employer who made allowance for her need for flexible hours.

Data Collection

Multiple approaches to data collection were used in this study to elicit the descriptions of living with fibromyalgia from the individuals' perspectives. Interviews, field notes and theoretical memos were used. A demographic data questionnaire (see Appendix E) was completed prior to the beginning of each interview to collect information regarding the age, occupation, length of time living with fibromyalgia, current status with FM, and any other currently existing disease or health condition.

Data were primarily collected through in-depth one-on-one interviews with each of the participants. The initial interview was guided by semi-structured, open-ended questions to facilitate participants' free disclosure of the phenomenon (Morse & Field, 1995). The second interview was conducted with another set of open-ended questions to clarify information from the first interviews and to validate the emerging themes. Both interviews were carried out in a setting selected by each participant to provide a
conducive environment within which to recount their stories. Four of the interviews took place in participants’ homes, three took place at a church, and one at an office. Trigger questions were used to stimulate discussion throughout the interviews. The interview questions for this study (see Appendix F) were generated based on the stated purpose of this study. The researcher kept field notes, written immediately after each interview, to record observations about the interview setting, impressions arising from the interview process, and any other emotional or non-verbal nuances surrounding the interviews since, according to Kvale (1996) and Morse & Field (1995), the verbal and contextual information surrounding the interview could form an important supplementary contribution to the taped data. Along with the field notes, the researcher also kept a reflective journal to write down insights and methodological decisions made from the data.

Each interview was audiotaped and then transcribed verbatim. The first interviews lasted from 45 minutes to one and one-half hours. All data from the first transcribed interviews were analyzed and categorized before a second follow-up interview with each participant was carried out.

Two participants were not able to participate in the face-to-face second follow-up interviews. Instead, they wrote out their responses to the questions and sent them to the researcher by mail. The reasons for this were that one participant mentioned that she preferred, and was better at, writing her thoughts down than speaking into an audiotape. The second participant had a flare-up of symptoms and was not feeling able to have a second interview in person; thus she wrote her responses and mailed them to me.
Data Analysis

The process of data analysis within the interpretive descriptive method is inductive and data collection and analysis occur concurrently (Thorne et. al., 1997). I repeatedly listened to the tapes of the interviews and read through the transcribed texts several times in order to immerse myself in the data as a whole (Cresswell, 1998). I jotted notes in the right-hand margin and assigned descriptive labels to each paragraph of the data that seemed to reflect a beginning indication of themes pertaining to the experience of living with FM. Small units of raw data from the transcribed texts were grouped into meaningful units, and these were then categorized according to similarities or differences among the participants' descriptions of their experiences. According to Polit and Hungler (1991, p. 510), "a theme might be a phrase, sentence, or paragraph embodying ideas or making an assertion about some topic." These themes were then organized into categories; the themes within each category were analyzed and the relationships of themes across categories were examined to delineate any commonalities or differences between them using the constant comparative method as proposed by Glaser and Strauss (1967). I regularly jotted notes in my reflective journal to clarify the relationships between the emerging themes. Thus, I engaged with the generated data to gain a sense of the data in its entirety, so I could "... capitalize on such processes as synthesizing, theorizing, and recontextualizing rather than simply sorting and coding" (Thorne et al., 1997, p.175) to classify or create linkages. The aim in the interpretive descriptive approach is to understand the overall picture of living with the phenomenon by questioning and interpreting the data as a whole, looking for "common patterns and themes within shared elements of a chronic illness experience and theorizing the
application of those common themes to an infinite set of unique cases” (Thorne et al., 2002, p. 443). The themes that were constructed from the conceptualization process were discussed with the thesis chairperson. Data collection and analysis continued until data saturation occurred. Finally, a description of the shared emerging themes was examined as a whole to create a body of nursing knowledge that would speak to the experiences of those who live with fibromyalgia (Thorne et al., 1997).

Rigor

Rigor or trustworthiness in this study was ensured by following Lincoln and Guba’s (1985) criteria for qualitative research: credibility (truth value), fittingness (applicability), auditability, and confirmability (objectivity). A study is considered to fit the first criterion of rigor, credibility, when the informants recognize the findings of the study as true to their experiences (Sandelowski, 1986). Several strategies were used to ensure credibility in this study. The interviews were quoted verbatim from the audiotapes. A second follow-up interview was conducted with each participant to validate the researcher’s interpretations of the emerging findings to ensure that the interpretations did truly reflect the perspectives of the participants’ experiences (Morse & Field, 1995; Sandelowski, 1986). Triangulation across data sources such as the transcribed interviews, reflective journal writing, field notes, memos and member checking were carried out to further ensure credibility and the congruence of the findings (Sandelowski, 1986).

The second criterion of rigor, fittingness, is achieved when the findings of the study fit into other contexts or groups of people outside the study situation and have meaning and applicability to them (Beck, 1993; Sandelowski, 1986). Purposive sampling was used in this study to ensure a rich and wide variation of the data collected about the
phenomenon (Morse, 1991). Continual comparisons were made between the narrative accounts of all the participants, ensuring that the data set contained both the typical and atypical elements necessary to increase its representativeness and the transferability of the findings beyond the study context (Sandelowski, 1986).

Auditability, the third criterion, refers to the consistency of the qualitative findings when another researcher or reader can clearly follow the decision trail used by the original researcher (Sandelowski, 1986). Auditability is achieved when another researcher is able to arrive at similar or comparable conclusions (Burns & Grove, 1997; Sandelowski, 1986). To ensure auditability in this study, I asked my thesis chairperson to review the first three initial transcripts with me to examine my interview questions, the steps that I used in my data collection, and my data analysis methods. I also kept field notes documenting how the data were collected, the settings where the data collection occurred, how the data were analyzed and how the themes were developed. Both the detailed records of the process of data analysis and the use of theoretical memos allow others to follow the logic used during the process (Sandelowski, 1986). To enhance consistency throughout the process of sampling, data collection, and data analysis, I discussed the quality of the decision trail and the decisions made with my thesis committee members.

The final criterion of rigor, confirmability, refers to neutrality or objectivity in qualitative research. Confirmability is achieved when the other three criteria of credibility, fittingness, and auditability are ensured and when there is the freedom from bias in the research (Sandelowski, 1986). With respect to personal bias in the research, I tried to be careful not to allow my own preassumptions, beliefs, and values about the
phenomenon to influence my data collection and analysis, but rather to allow the participants' accounts of the phenomenon to emerge from the data (Lamb & Huttlinger, 1989). To further ensure credibility, I regularly obtained input from my thesis committee regarding the logic of my data analysis process and employed member checking to ensure that I did not introduce my own individual biases. I kept field notes regarding the method of participant recruitment, the impact that the informants and researcher had on each other, the specifics surrounding each interview, and the nature of the setting. I also documented my own personal feelings and reflections related to the study to ensure reflexivity. I constantly checked my relationship with the participants, seeking to maintain minimal influence upon their stories during the research process. I also validated the emerging findings with the participants during the second interviews to transcend any possible individual bias.

Ethical Considerations

The following measures were taken to protect the rights of the participants who took part in this study. Prior to the commencement of this research, written approval to conduct the study was obtained from the University of British Columbia Behavioral Sciences Ethical Screening Committee for Research and Other Studies Involving Human Subjects. Upon ethical approval, participant recruitment was sought through the offices of two rheumatologists' clinics, the British Columbia Fibromyalgia Society, and through a key informant. Information letters about the study (see Appendices B1, B2, and B3) and a participant information letter for distribution to potential participants (see Appendix C) were given to the rheumatologists, the Fibromyalgia Association, and the key informant. This participant information letter provided potential participants with a full written
description of the study’s purpose, the nature of their involvement, the potential benefits of the study, and the rights of the participants to ensure that they had made informed consent. Interested individuals called the researcher directly to get more information about the study and the names of potential participants were also given to the researcher by the key informant and by others. Arrangements were made for interviews with the participants at a location convenient to each individual.

Prior to each interview with the informants, the researcher informed the participants verbally and in writing of the nature and purpose of the study, what their involvement entailed, and how the data would be collected, handled and disseminated. Informants were told that their participation was entirely voluntary and there were neither risks in nor any financial remuneration for participating in the study. They were also informed of the possibility that some emotional feelings might accompany the interview process as they recounted their stories, or they might obtain indirect benefit from sharing their thoughts and feelings with the researcher who would be attentively listening to their stories. They were also informed that should they develop physical or emotional problems the researcher would be ready to refer them for counseling services if needed. (In fact no participants needed such referrals during the interviews). Finally, participants were told that they could withdraw from the study at any time without any effect on their current or future treatments, that they could refuse to answer any questions during interviews, and that they could terminate the interview at any time.

To ensure anonymity, documents, audiotapes and transcriptions were coded with numbers rather than with the participants’ names. Only the researcher and the thesis committee had access to the data. A third party was hired to transcribe the recordings but
she had no access to the identities of the participants. The transcribed interviews, disks and audiotapes were locked in a file cabinet and only the researcher had access to them, and data stored on a computer hard drive was accessible only by the researcher's password. Pseudonyms were used throughout the written transcripts to protect the identities of the participants. The audiotapes and transcripts were scheduled to be destroyed at the end of the project after all scholarly reports had been written. A summary of the study’s findings was to be given to the participants upon the completion of the study, and written consent will be obtained if any transcripts should be proposed to be kept for future educational and research purposes.

Limitations of the Study

The principal factor that could have affected the quality of the data generated was the researcher's lack of experience with the research process, a lack that could affect the quality of the data generated from the interviews.

One of the most significant limitations in the study may be that those who had the energy and the commitment to participate in this study were likely to have been those who have developed successful strategies to manage their condition. It is possible that certain people with FM lacked such strategies, and were feeling too depressed, too tired, or in too much pain to have volunteered for this study. The more articulate members of a group tend to volunteer for a study (Morse, 1995), a fact that may limit the applicability of this study to the experiences of less articulate persons. Consequently, the findings in this study might only reflect the perspectives of the specific group of people with FM who have developed successful coping strategies and perhaps cannot, therefore, be generalized to others who did not volunteer.
Certain selection criteria were used in this study. Some prospective participants were excluded on the grounds that they could not participate in the interview due to their unfamiliarity with the English language since the researcher was not able to engage an interpreter. Accordingly, the findings might not represent the perspectives of non-English speaking people with FM. In addition, since the sample size was small, involving only eight participants living in the Lower Mainland region of B.C, the findings cannot be generalized as representative of all people with FM. Moreover, since participation was voluntary and because seven of the eight participants were female, the final pool of participants may not represent the general population of people living with fibromyalgia. Furthermore, the participants described their experiences within the context of their lives—that is the meaning constructed from personal, interpersonal, social and cultural reactions to illness. The descriptions of the experiences of these participants may differ from other people with FM who live in different cultural and social contexts. Finally, according to Sandelowski (1995), the way people recount their stories may change over time. Thus, it is not known whether the different ages of the participants, placing them at different developmental stages in their lives, or the differing lengths of time they had lived with the illness has affected their perceptions of their experiences of living with FM.

Summary

I have used an interpretive descriptive approach to collect data for this study. Eight participants were obtained in accordance with the purposive theoretical sampling method. Data was generated through semi-structured interviews. The tapes were transcribed and reviewed. Thematic analysis revealed themes common to
participants' experiences of living with fibromyalgia. I ensured rigor through addressing the issues of credibility, transferability, auditability and confirmability, and I took applicable safeguards to meet ethical considerations as mandated by the UBC Behavioral Sciences Ethical Screening Committee. Finally, the limitations of the study were identified and described.
CHAPTER FOUR: FINDINGS

This chapter presents an interpretive description of the participants’ experiences of living with fibromyalgia. This description evolved as the researcher used the constant comparative method throughout the data collection and data analysis process. Essentially, the participants in this study describe how fibromyalgia has affected their lives in many ways.

Emerging themes from the interview data as shared by the participants were: first, living with the symptoms of FM, including the sub-themes of living with the complex nature of FM and the impact of the symptoms; and second, strategies for the management of FM, many of which relate to finding and maintaining a balance, as well as utilizing support networks. Embedded in these two broader themes is a thematic thread concerning the social, health care and political contexts within which individuals live with their condition.

Living with the Symptoms of FM

Participants mentioned that they experienced a wide range of symptoms associated with FM. This study’s findings suggest that there are numerous dimensions of living with the symptoms of FM, which include the sub-themes of experiencing a wide range of symptoms, living with the complex nature of the symptoms, and living with the impact of the symptoms.

*Experiencing a Wide Range of Symptoms*

All eight participants in this study stated that they experienced a wide range of symptoms associated with living with FM: pain, sleep disturbance, fatigue, irritable bowel, flu-like symptoms, night sweats, nausea, and feelings of stiffness. I will discuss in
this section only those symptoms common to all the participants in this study: pain, sleep disturbance, fatigue, mental cloudiness, and irritable bowel.

*Pain as a Constant Enemy*

Pain was a symptom reported by all the participants in this study. They were united in describing pain as the constant, ever-present enemy as part of their daily experience living with FM. As one participant remarked, “You have to learn and accept that you’re going to have pain forever. There’s never a day without pain.” Another participant emphasized how the constancy of the pain had affected her:

Well, sometimes it’s a vicious enemy. Sometimes it’s annoying and distracting. It is constant. To my feeling it’s severe. I’ve learned in these years to try to cope by distracting or trying to be positive, all the way to trying to mediate and do deep breathing but it is a constant. It is a constant! And I’m aware of the fact that I’m feeling the pain more acutely than maybe a healthy person and I try to temper my reaction then because I know if something hurts me, it could be overblown to my neurons, my nervous system and it feels like it’s overcharging all the time and hitting me all the time and I just try to deal with it [on] a minute-to-minute sometimes level.

In addition to the constancy of their pain, participants also found that their pain varied in nature and intensity. The pain participants reported experiencing on some days was sharp, shooting, stabbing, or burning. A participant described this kind of pain as follows:

It feels like the skin and tissue kind of pain. It’s a burning type pain where I can’t stand anything on my skin for very long at all including say a finger. It occurs quite frequently and even to touch or light pressure. It feels like I’m walking on sharp stones and it’s just like I can’t take another step without just really an uncomfortable pain.

On other days, participants noted that their pain could be a tingling feeling, or a flu-like aching sensation. They variously described this pain as aching, dull, annoying, nagging, distracting, or manifesting itself in the form of generalized aches and pain.
In addition to the different types of pain perceived by the participants, the location of the pain also varied: it could be in the arms, legs, knees, head, neck, jaw, face, back, joints, or all over the body. One participant described the pain she experienced:

Different types of pain. There's a real stiffness as if you haven't moved a joint. I notice especially in my ankles and my knees. Other times it can be a sharp pain. So the type of pain can vary. And then there's just like a total weariness...so there are various kinds of pains that I experience. And no day is the same. No week is the same.

The varying nature, intensity and location of the pain had caused the participants to experience difficulty in making sense of their pain:

There are days when the pain is very localized, but there are other days when if someone asked me to say exactly where I hurt, the only answer I could give would be everywhere. Often the pain is intense in one location, and then switches to another. It is there. Not there. Then somewhere else. Crazy making.

The informants also reported that their pain could be triggered or worsened by all kinds of ordinary physical activities. One participant explained:

Physically I'm in a lot of pain much of the time and the pain is made worse by all kinds of activities, particularly standing too much, walking too much. Carrying things is really bad. Kinds of periods of extended efforts of repetitive motions will set it off.

Even the daily friendly gestures in life such as being touched, rubbed against, hugged or being held—things we generally assume are not painful—triggered pain in people with FM. One woman mentioned that it was painful even to be touched or to have any type of pressure exerted on her body:

Well, my body hurts and for somebody to grab me, or grab my hands or my arms or press against me is painful, and even to sleep, I liken myself to the princess with the pea in the bed because any crease bothers me. I have to buy my night attire, that doesn't have heavy seams because they would bother me.

Bending over, crouching down, and changes of position involved in carrying out the daily chores of life could cause pain for participants. They had to make decisions each time as
to whether or not to carry out certain activities since they knew that those activities would increase their pain. As one participant described it:

For me to crouch down, to squat...it's pain. To get up, I'm grabbing onto a countertop or a tabletop to pull myself up. I look awkward...I feel stupid and I get mad, for a moment, thinking, "Crying out loud, this is...this is insane." But it's real. And...how many people when you're going to go and reach for a casserole dish, for instant, or a pot that's on the bottom shelf...how many people pause for a moment and think it through, whether or not they really want to go and get that thing because they know...they know it's going to be painful to go ahead and get down there... That's not normal.

The constancy and varying nature and intensity of the pain can be so overwhelming and frightening that it is hard to manage. As one participant put it:

Some days I can manage it and some days I give up and I simply don't do anything. But it's always there and is very annoying and sometimes it's very frightening depending on the type of pain.

In their descriptions of life with FM, participants mentioned that the constant presence of pain was a pervasive enemy that existed daily and, indeed, was present in almost every minute of their lives. The nature and the location of the pain varied unpredictably which made it hard for them to manage their daily activities. Carrying out the usual common activities in life such as lifting, squatting, carrying things, and a variety of other physical movement triggered or worsened the intensity of pain which brought about hesitancy in carrying out such tasks. Participants found such experiences of pain to be very debilitating, affecting them physically, mentally, and emotionally.

Sleep Disturbance and Fatigue

Sleep disturbance and fatigue were another two common symptoms reported by all the individuals in this study. According to the participants, sleep disturbance came in the form of not being able to fall asleep readily, or of awakening after sleeping for only a couple of hours. One participant said, "You just all of a sudden wake up in the middle of
the night with your eyes wide open. Nothing, no sounds have disturbed you, and nothing's wakened you up." The participants' difficulties in falling asleep seemed to be due to the presence of pain or to being awakened by pain; at times the sleep disturbance seemed to be related to the difficulty in finding a comfortable sleeping position. One participant said:

At night when you want to sleep, one leg is stiff, the other leg is numb. You know. Your bottom hurts, your shoulder hurts. If you put your head a certain way your hand hurts. If you put your neck a certain way your neck hurts so you're forever trying to shift to a better position and so you know you end up giving up in many areas and the worse you sleep at night, the worse your next day is. So it's a circle and the circle is a battle.

Because they were not getting enough sleep, the participants also experienced fatigue. But, according to the participants, the fatigue they experienced differed from the usual feeling of tiredness that the rest of us encounter because their fatigue was unrelenting, did not readily dissipate with added rest or sleep, and was fairly persistent regardless of the measures taken to relieve it. The participants described their fatigue as a "muscular fatigue" or a sense of "total weariness" causing them to "crash easily" and be "not able to move another muscle". In addition, they found themselves not able to carry out routine life chores or accomplish all the other tasks they wanted to achieve during the day. One participant explained:

I'm very tired, not tired in the sleep sense, but fatigued. It's like putting 100 lb weights on and tying them to one hand and a 100 lb weight tied to your other hand and then you're trying to hold these things. That kind of muscle fatigue. And I just want to go to bed again! So I go back to bed. And I'll set the clock for an hour, an hour and a half, and wake up and I'm just dozy. I try to function and I may be doing something at the computer or maybe trying to clean something, clean up around the home; I don't get a lot accomplished and I find that I spend a good part of the day fighting going back to bed or lying down and resting.
This inability to fall asleep, in spite of feeling extremely tired, not only increased their exhaustion and but also heightened their sensory perception of pain. One participant shared her experience as follows:

There are nights that I can't fall asleep when my body just feels dead tired all over and hurting and I'm just lying awake... and my brain won't let me fall asleep but my body doesn't want to stay awake and it's very painful. I haven't got all this figured out yet.

Participants mentioned that at times when they had better, more relaxed sleep, they found themselves in better shape to deal with their pain. As one participant said, “I find that when I sleep better, the pain seems to be a lot more tolerable.” Another participant further explained how the symptoms of pain, fatigue, and sleep disturbance were interconnected:

What I find is that it’s not just the pain and the fatigue, it’s also the sleep disorder, it’s the non-restorative sleep, and it’s a vicious circle because if you don’t get enough sleep you feel pain more acutely. And when you feel the pain more acutely you’re more tired and unable to sleep well. If you can break that first cycle and get some good sleep or some good pain control, it really does help.

As revealed in the statements of these participants, the abnormal fatigue that is another common symptom of FM seems to be unrelenting and not relieved by rest. Moreover, participants reported that pain, sleep disturbance, and fatigue are interconnected in a vicious cycle. That is, the participants usually mentioned their fatigue in relation to the pain as the constant presence of pain interfered with their sleep and rest, leading to fatigue. While pain and sleep disturbance were reported as precursors of fatigue, fatigue also intensifies feelings of pain, thus making it harder to achieve restorative sleep.

*Mental Cloudiness*

Mental cloudiness or “fibro fog” was another symptom alluded to by the participants in this study as part of their having to live with FM. Participants found their
minds did not function as acutely as they did prior to their getting FM; they experienced memory loss and other cognitive difficulties that affected their judgment, concentration, attentiveness, and ability to make good decisions. According to the participants, their mental cloudiness was also affected by other symptoms of the condition. The first cause mentioned was pain:

My mind seems to focus on the incredible amount of pain; it’s so painful that your mind is just not able to take in any information. I couldn’t read, I couldn’t literally see, I couldn’t think.

Mental cloudiness was also a side effect of some of the drugs used to treat the condition. One participant discovered this in a particularly ironic fashion:

I was taking so much medication for pain that it impaired my memory and cognitive functioning. I work in a pharmacy counting pills, making compounds. I couldn’t remember the formulas for making skin lotions, morphine solutions. I couldn’t remember things anymore.

Mental cloudiness was also worsened by fatigue resulting from lack of sleep:

It [FM] does keep me awake at night a lot because of the pain of it, it does keep me awake a lot and I will get tired when I’m going through a kind of a spell of it. It seems to come in spurts and when that’s happening it really impairs my sleep. I become emotionally quite volatile. I lose my temper more easily and cry more easily, and things like that. That impairs my judgment sometimes. It’s hard for me to focus and concentrate on anything.

The participants reported how “fibro fog” had significantly affected their memory and daily functioning. One participant said:

I found that it was the FM and that is part of it you know, just things like direction, memory, losing track. I can see the same movie month to month or read the same book from week to week and it appears new to me. Unless there’s something specific that jumps out, I don’t remember them. I go to the library and I pick books for my child and sometimes from week to week I’m taking the same book and I’m not even aware of it.

Although the side effects of medication sometimes contributed to participants’ mental fogginess, in general, participants associated “fibro fog” with pain, sleep
disturbance, and fatigue. They felt that these symptoms were all interrelated: pain
interfered with sleep and mental alertness; the sleep-deprived state in turn led to
increased fatigue and impaired mental functioning; the more tired the participants felt, the
more mentally cloudy and emotionally labile they were; the combination of all these
symptoms limited their capacity to deal with pain and other added stress brought about by
FM.

**Irritable Bowel Syndrome**

Irritable bowel syndrome seemed to be another common symptom of the
condition. Six of the eight participants experienced this symptom. One participant
recounted:

> The irritable bowel syndrome is not very pleasant but what happens with me is
> that it builds up to a crisis that resolves sometimes in an hour or two, sometimes it
> takes all night or up to two days in that I start with a lot of bowel cramping, pain,
> go to the washroom. It starts as constipation and only ends when I have totally
> cleared out the liquid run, and it’s very painful.

Another participant was even more explicit in her description:

> It’s like somebody ripping your gut open. Tremendous cramps! A lot of gas! You
> think you were having a major attack of appendicitis. You can have bowel
> movements that are diarrhea to constipation to everything’s working and it’s
> going to cause great discomfort.

While irritable bowel syndrome is a symptom of FM itself, the participants noted that it
could also be triggered by the various medications that were used to treat pain or other
symptoms:

> So as far as the pain medications they cause side effects with the irritable bowel
> syndrome. Sometimes I use Buscopan® that is for relaxing the bowel, sometimes
> I just rely on the Flexeril®, sometimes I take that during the day for the various
> muscle spasms that happen, or sometimes I’m using it at night to help sleep. So
> that’s a whole grab bag of things. I recently had a flare-up with my stomach, that
> necessitated two of the stronger stomach medications, Losec® and Cytotec®.
Cytotec® causes diarrhea, nausea and discomfort. You know it's a nasty cycle and I feel like a pharmaceutical garbage pail at times, but I have to function.

The participants also mentioned that the irritable bowel syndrome interfered with their work as they needed to visit the washroom frequently. Some participants explained that they tried to regulate their diet or avoid anything that might trigger an attack. One participant recounted:

Diet can regulate that. I know for example, nuts...I'm not allergic to them but I have to be very careful because if I want to have an irritable bowel attack I'll just go and eat a whole handful or a bag of nuts and I'll get it. So I know nuts does it. Heavy fats...like cooking oils for instance. Those are two classics that I'm aware of. Too much roughage. If I took a great big bowl of salad and just gorged myself on it...thinking, "Gee, this is healthy stuff" I'll get an attack. It doesn't mean I cannot eat that stuff but boy do I have to moderate it. I should have to eat it and moderate it. So, we have control over that symptom.

As shown in the foregoing narratives, participants experienced a wide range of symptoms as part of their living with FM. All these symptoms, according to the participants' perceptions, worked together in a vicious cycle that disrupted their lives. Irritable bowel symptoms (reported by six out of the eight), on the other hand, seemed to most participants to be associated with or aggravated by the ingestion of food or drugs. In addition, participants seemed to perceive that they were sometimes able to exert some (albeit limited) form of control over the irritable bowel symptoms – for example, by moderating their intake of certain foods. In contrast, their symptoms of fatigue tended not to improve with rest, their pain did not respond well to medication, and they had no antidote for their mental fogginess. Moreover, these three symptoms seemed interrelated in a vicious cycle that disrupted their lives and complicated their attempts to successfully manage any one symptom of pain, fatigue, or mental fog.
Living with the Complex Nature of the Symptoms

Not only do participants experience a wide range of symptoms in their daily experience of living with FM, they also reported that their symptoms are complex in that they are constant, varying, unpredictable and invisible in nature. This section will focus on these aspects of the symptoms of FM.

The Constant Nature of the Symptoms

In the earlier section of this chapter, I discussed participants’ reports that pain was their constant enemy, always present in their lives. In addition to the daily presence of pain, these informants also recounted that they suffered continually from other symptoms every day and almost at any time during the day. One participant explained:

For me, the idea of constancy of pain, one might think in the terms of “Well, is it like having a toothache that’s constantly there?” Well, no, because of the many different symptoms associated with fibromyalgia. If it’s not one thing it’s something else. For example today I feel my muscles don’t feel as sore though there’s stiffness there and in 10 or 15 minutes if I’m to get off the chair and just try to walk it will feel like my feet are being broken. That’s very typical. But where’s the constancy? Well I also feel very nauseated. Like I have the flu. Is that painful? Well, not painful so much but when you feel like you’re going to throw up you feel flush; it’s certainly miserable. If it’s not that, it could be the irritable bowel system that is a symptom that I have that is occasionally my irritable bowel triggered and just when I think, “Hey, this is...I’m not having too bad a day” and then I start getting abdomen pain; sometime gut-wrenching where I’m almost doubling over. Or I’ve got to make a beeline to the bathroom – real quick. And I’m in a lot of pain there. So, if those are all gone or they’re under control, a severe headache will evolve. I mean we all wake up with our aches and pains but we don’t go through the range of when one is laid to rest temporarily then another one kicks in. That one’s gone and then another one pops up, or two crop up. So, for me that’s what I’m talking about in terms of being in constant pain and discomfort.

This participant gives a comprehensive description of one of the life-changing and overwhelming aspects of FM: the presence at all times of one (but usually more) of the distressing and debilitating symptoms that characterize this condition. This constant
presence of symptoms, according to participants, is a significant contributor to oppressiveness of life with FM.

*The Varying Nature of the Symptoms*

Not only are the symptoms of FM constant, they are also varying in nature. Not only does the pain vary both in its character and location, but many other symptoms associated with FM are likewise non-specific and variable, appearing in various forms all over the body. Among other responses to this presentation of FM symptoms in varying forms, participants noted that this variability made it difficult for the participants to determine whether the symptoms they experienced were related to fibromyalgia or had originated from other physiological causes. For example, one participant said:

One of the pains I have is a chest muscle pain that is quite normal; those are trigger points that we have in the chest and it runs through to the back and it means that your hands get numb, your fingers tingle and those are the ones I panic with. I actually don’t want to move because you think it’s the heart or something.

Because the symptoms of FM were varying and mimicked the symptoms of many other illness conditions, the participants explained that it was important to have them checked out medically:

You don’t assume that every ailment, whatever you experience, is a symptom of fibromyalgia related. That’s another important thing I’ve discovered. I can’t assume that the gut-wrenching pains that I’ve had in my stomach is necessarily irritable bowel syndrome. So it’s wise to go and have it checked out. For a man having a prostate, to have it checked out and not assume, well I’ve got this symptom but that’s got to be fibromyalgia... It does not mean that because a person has fibromyalgia and it’s self-maintained that they are immune from getting any other ailment.

While six participants in this study had histories of traumatic injuries prior to their diagnosis of FM, only two of them mentioned that it was difficult at times to determine
whether the pain they experienced was associated with FM or if it arose from their past accidents. One of the participants with such a history said:

I might be a slightly odd case, but I'm probably not, because I think with a lot of people with fibromyalgia there are precipitating factors. I was in a motor vehicle accident and I had not only a really severe whiplash injury but also a head injury and I developed a mild right-side paralysis and some cognitive problems so it's slightly unclear to me sometimes that thing is happening as a result of fibromyalgia or that thing is a continuing result of that accident.

Another participant with a similar history commented:

Um, there are times when I’m asleep and then I’m awakened out of a sound sleep with pain as well. In a certain area. And sometimes I wake up with a numb leg so I’m not sure that’s related to my injuries or the fibromyalgia or both.

As these participants suggest, it can be difficult to assess whether past injuries or current health issues unrelated to FM might be producing symptoms. This is one of the ongoing challenges for people with FM: on the one hand, the symptoms FM sufferers experience are so variable that almost any symptom that occurs might be one that could be attributed to the FM; on the other hand, symptoms might be due to a different health problem, unrelated to FM. Each time a different symptom occurs, a person with FM must assess its meaning with respect to both these health possibilities; participants’ descriptions of this process suggest that this ongoing dilemma contributes to the stress of living with FM symptoms.

The Unpredictable Nature of the Symptoms

The third characteristic defined by the participants pertained to the unpredictable nature of their symptoms. Participants explained that they were not always able to foretell what symptoms might affect them at any given moment:

I can’t predict when I’m going to get a headache next. I can predict to you that when I get out of bed I know my legs are going...my feet are going to be very fragile, very sore for the first few minutes until I get going. I can predict that
when I go for my exercise walks that I will... I was going to say that I could predict that I won't feel pain, yet that’s not accurate... that's not right. So I can’t say that. So, there’s predictability about it and there’s unpredictability. I guess other people say it’s unpredictable; maybe they’re referring to a specific where it’s going to hit them next. Whether it’s maybe the lower back. My lower back hasn’t been too bad these days. A couple of weeks ago it was horrendously painful. So I couldn’t predict that.

While sometimes the experience of pain, fatigue or other symptoms, was "earned from doing things like a normal person," sometimes it was just there, present without any triggering factors. As one participant reported:

Again, it’s [fatigue] like with the pain. Sometimes you earn it, sometimes it comes, even if you think you’re well rested and coping, it can hit you anyway. I have been stuck before, in the car, unable to drive it, having to pull over and be rescued by friends because I was not safe to drive because the fatigue just shut me right down. So you learn to cope but again it’s unexpected, not always earned, you know. And sometimes just totally out of the ordinary.

The unpredictable nature of the symptoms affected the participants’ ability to plan ahead in their life activities. One participant stated:

The generalized pain and the weariness. And you don’t know when they are going to affect you and when it’s going to start to be a little better so you can’t really plan anything in your life because you just don’t know how you’re going to feel when that time comes around.

Another participant emphasized further the unpredictable consequences of the symptoms of FM:

On some days, it is okay to cook dinner or do other tasks whereas other days the same manageable tasks seem painful. Some days, when you have to cook your dinner, that in itself seems to be the most overwhelming task of the day. So there are lots of things that are very painful. And on good days, peeling the carrots is fine. On another day, peeling the carrots or peeling the potatoes can be the most painful thing you did.

As well as the physical impact of the symptoms, the participants also stressed the emotional and psychological effects of their unpredictable symptoms. Participants reported that, on some days, the intensity of their symptoms caused them to “cringe and
to be “emotionally more volatile,” to lose their tempers easily, to cry easily, or to
snap at their friends, families and others more readily. One participant explained:

I find it’s a vicious circle a lot. Emotionally...sometimes I feel I’m on the edge emotionally. Like I want to start crying. That is...maybe an odd thing you know, to say but ah...maybe it’s just the frustration of everyday waking up feeling like I have the flu but I haven’t got the flu. But waking up, feeling like you have the flu...like that’s how I feel right now. I feel nauseated and then going to bed, feeling the same way only to wake up the next morning and nothing’s changed... What do you do with that? I guess you try to...you just ignore it. You try to just live with it and don’t allow it to...to control your day-to-day activity. But I find it does! At times. Because when I’m feeling that way, it’s like having an abscessed tooth. And you start getting grouchy. And you snap at your family or something and it takes a real effort for them to kind of realize it’s...there’s a reason why that just happened and then I’ve got to kind of realize “yeah, I know because this is how I’m feeling.” But not to use that as an excuse either.

All the participants stressed that the unpredictable nature of their symptoms had a considerable impact on them emotionally and psychologically. For example, one participant said:

I don’t have a psychological problem. I get depressed thinking of going on with each minute of each day because you never know when pain hits you. One minute you’re fine, the next minute you can’t walk. Third minute, you know, something else goes wrong. Every time something else happens. Fibromyalgia is one of the most irrational illnesses I ever dealt with. You know if you break your legs they can set it and you can get better but you don’t have that prognosis for people with fibromyalgia yet. I do find it challenging and I do get depressed and you know I’m not a depressed type of personality. But I do get depressed because when you wake up in the morning you can’t get up. Doesn’t make sense, you know, so fibromyalgia does affect the mental health and the well-being.

This same participant strongly rejected the view that depression in people with FM arose from any other cause than the condition itself, noting further that “It’s not that because people with fibromyalgia have mental health problems first. The illness comes first; the depression comes later.” The participant’s foregoing comments suggest that, for this individual at least, the unpredictability of the disease was a major source of emotional stress that resulted in depression. Other participants explained that they too found the
challenge of living with FM unexpectedly difficult emotionally. The condition seemingly reduced their ability to handle additional stressors in their lives:

One of the really big things for me that is difficult is that I do not handle stress very well. I get overwhelmed very easily; that was not true in the past, if it was true I was able to hold things together until the stressful situation was over, go off somewhere and then wail! Now I am more likely to break down in the middle of something, that I find very humiliating.

The stressors that precipitated emotional distress included environmental stimuli such as artificial light or noise. The resulting stress then could trigger a flare-up of other FM symptoms. As one participant stated:

Stress is a major factor as far as I’m concerned. It often is the trigger that sends me into what is classically called a flare. I’m also highly sensitive to both light and noise. When eating in a restaurant, I request a table not directly under a speaker. Even when away from speakers I ask that the volume be turned down. Florescent light ballasts that create that terrible low humming or buzzing sound drive me crazy while others don’t notice the noise. Bright light makes me uncomfortable. In restaurants, I will sit in a booth where there isn’t direct light shining in my eyes.

Natural environmental stimuli were also found to be such stressors by the participants. As one participant noted:

Particularly in the first two years when I was at my worst [with FM]. I was hypersensitive to noise, smell, could not tolerate light and actually vibrated on the inside of my skin or body. Now I can tolerate certain noises better than others and can tolerate some light but have problems with sun exposure. I am actually aware of stress as it causes a sensation of having raw nerve endings tingling in my body. If I go out at night, I find my whole body reacting and unable to calm down as if I have just received a shock to my system. So I try to avoid any evening outings unless there is a special occasion.

It is clear from the participants’ discussions that it is a source of frustration and acute emotional distress that they are not able to consistently predict what symptoms they will experience at any given time, nor to what extent they will be affected by these symptoms. This uncertainty has made FM an extremely challenging condition to live with and
manage, for this unpredictability tends to undermine the individual’s ability to map out a successful strategy for coping emotionally and psychologically with the physical effects of FM symptoms. Instead, those with FM are continually caught off guard by their symptoms, and must always be striving to adjust anew.

The Invisible Nature of the Symptoms

The invisible nature of the symptoms of FM presented another additional challenge for the participants. As has been noted, the symptoms of pain, sleep disturbance, fatigue, mental cloudiness and irritable bowel syndrome, were not readily supported by distinct objective data thus making it difficult for health care professionals and others to either identify or validate the presence of these symptoms.

Since there were no biochemical data to support the presence of FM, it was difficult for physicians to readily secure a diagnosis other than by the elicitation of tender points. Most of the participants in this study reported that they underwent numerous tests before a diagnosis was made. One participant said:

I remember a lot of blood work and some chest X-rays being done. All came out negative. The testing was likely due to my continual complaining that I just was not feeling well; fatigue, flu-like symptoms, breathing problems, severe muscular and joint pain. After it was suspected that I had FM it was pretty straightforward. I went to a rheumatologist and he confirmed the diagnosis.

The long search for a diagnosis created tremendous stress for the participants and at times created tension in the doctor-patient relationship. Two female participants in the study stated that their physicians, unable to find known biomedical explanations for their symptoms, were judgmental toward them, claiming that the symptoms were “all in their head” or were “women-related problems.” Similar judgmental attitudes were also found among nurses. One participant shared the following unpleasant experience:
I went to the hospital and I have never been so angered in my life when one of the nurses walked by and somebody asked "what's wrong with this lady?" "Oh! you know...the usual...menopause" or something like that. That’s what was thrown in my face. And I thought, "you know what?" I wanted to get off that ambulance – I was on those beds, I wanted to choke him. Say "you take what I feel right now, I’ll keep doing the work, I’ll do your job, you take what I have, I’ll give it to you gladly, how dare you take one look at me and say, oh, you know...the usual female, 45, 48 whatever I was, it must be menopause." It is not taken seriously. We are called complainers. I have one document from one of the doctors that said that I have psychological problems, that must be my marriage, that I should talk to my husband to see what is going on there. I simply told him that if I need a psychologist, I will see a psychologist, I am here to ask you a medical question. I have a lot of pain and it wasn’t validated at all and it took me after six years only then I got my disability too. That gives me a lot of anger against the medical profession. The medical profession does not take it seriously. I know there are doctors who will absolutely not sign disability papers for you. They look at you. You look healthy. I have one doctor who wants to put me on some heavy drugs for depression.

Four participants in this study reported that they had not encountered this problem (having a physician describe their FM symptoms as a "psychological problem" or something that was "all in the head"). These four participants, however, were well known to their physicians before the onset of their FM, and their physicians’ previous knowledge of them may well have made a difference in the diagnostic processes in these cases. Nevertheless, all participants were aware of the tendency among some health care professionals to view FM as a non-biomedical condition and to discredit the symptoms experienced by people with FM. They were also aware of the social stigma surrounding fibromyalgia. One participant who had worked for many years in the nursing profession observed:

I was a nurse in the emergency department and from time to time we would always have women come to be triaged, and they would come with some kind of complaint and then, in their history, they would be suffering from fibromyalgia and they were taking anti-depressants for the most part of it. Umm, I used to think it was kind of a catch-all disease that women seemed to have...just an emotional problem that seemed to be prevalent among women. Until I developed it.
This nurse’s comment about her colleagues’ attitude (and her own, prior to her diagnosis) toward women with FM suggests that some nurses, like physicians, attribute FM to psychological or emotional problems.

Some of the informants found that neither their physicians nor their friends and family were prepared to validate something that had no objective criteria for diagnosis, and that furthermore left them looking healthy. One participant said:

FM is an invisible disease, syndrome, condition... I think that’s quite accurate. I will have friends that will come up to me, “Hey, you’re looking good.” And I’m feeling absolutely the pits. But you know, unless a person is sneezing and snuffing and their nose is really red, can you often tell that they have a cold? Short of hacking in front of us.... Can you identify somebody who has diabetes? I can’t identify somebody in a crowd who is a diabetic. We can say that with a whole variety of illnesses. This thing being invisible is that...well, many of those other illnesses though they may have the appearance of being invisible can be tested and there’s something concrete. And it seems that medical science lives so much...on the objective of course, test results, blood tests, x-rays, MRI, CT scans, whatever they go through and when you see something physically on the film or under the microscope, they can make a definitive diagnosis. How does someone receive a person coming in and the person saying, “You know, my body’s, my joints are just throbbing, my knees feel like they’re...they will not support any weight” and you go through scans, you have them x-rayed, you go through...are those things called MRI and nothing shows up. So, what does a doctor conclude? Well, the person is visibly in pain or is saying he or she cannot stand very long, certainly cannot run, feels pain crouching down, standing up and yet the tests that have come back don’t show sufficient enough evidence... well, does that mean that the person is lying? Does that mean the person is imagining it? Does that mean that the test results are wrong? That’s not.... that’s a dilemma. And I think a lot of people with fibromyalgia end up having to face that doubt.

Further, participants stressed that their illness might have been more credible to physicians had there been more specific objective data to validate FM beyond just the “tender point” count:

If they [physicians] could develop something more specific than the eighteen tender points and the other things that they look at when they want to diagnose you with FM; if they could actually test the neuron transmitters that are in excess and the ones that are reduced; if you could find some sort of proof... ‘cause, in
my experience, unless you can show people, unless you can show actually show them something, people just don’t believe or understand or support.

This comment suggests a frustration not just with the attitude of physicians, but also with the failure of the medical community to find better (and more clinically admissible) ways to diagnose FM. Two female participants in the study wondered whether there was another aspect of the effects of FM’s invisibility: they thought that the condition might be more readily acknowledged or recognized if it affected men more than women. One of them remarked:

I haven’t heard of many men and if it is a disease that affects all men and if more men were known to have this condition it would be seen as a more glorified thing. The way it is right now is it is seen as a “women’s problem” and kind of like the nineteenth century diagnosis of hysteria, so doctors tend to see it as another women’s emotional problem instead of a valid disease.

This perspective was not shared by all the participants; another woman in this study knew of a man with fibromyalgia who has encountered the same disapproval as female patients with FM. She said, “There was a gentleman who couldn’t shovel his snow and his neighbors looked down on him because they said he was lazy.” Thus, it seems that regardless of the gender of the individuals experiencing FM, the invisibility of the symptoms has created similar problems.

Participants explained that the invisibility associated with FM created additional difficulties for them within their families. It took some time for their families to believe and understand what they were going through mainly because they looked so well and yet were not able to continue carrying out all the usual household roles that they had filled before becoming ill with FM. One participant who had FM for seven years stated that it took a long time for her daughter to finally understand her condition a little more and to start to be helpful with the household chores:
Much of this is invisible so unless someone knows me really well, they can’t tell what the cues are...my daughter thinks it’s helpful she has always lived with me. It’s only the last year and a half that she started to figure out, “Oh you are in pain” and it was also during the same period that she started to be a little more helpful now. I can go grocery shopping, come home, leave the things in the trunk, and come inside and she will go out and carry them in. That makes a big difference. But that’s quite recent. Before that she would simply refuse.

Another participant shared that her experience was even more devastating when her family members alienated themselves from her. Then, when her pain, fatigue, and other symptoms got a little better, she said they expected her to fulfill her share of the household responsibilities even though she tried to explain that she was not as well as she looked:

I find the most disturbing thing in my immediate family was that everybody wanted to escape me. Because they didn’t know how to deal with me. And then when I got better there was the simple expectation, “Well you look fine, so go do it.” And when I tried to explain it to my children, they would say, “Well that’s your problem.” So I think that family members don’t really understand it and because...they can’t see it and they have no sympathy for you. They could care less because they don’t understand it, they don’t see it. They simply think, “Well, for Pete’s sake! I work nine hours a day, can’t you do the simple vacuum cleaning or household or cooking?”

Such a lack of validation and support from family members can be particularly hurtful. All the participants in this study said that they wanted society-at-large to have a greater understanding of the invisible nature of their condition through education.

Participants also indicated that they felt many physicians favored working with medical conditions with clear-cut etiologies supported by objective diagnostic data and in situations in which they could see results of their treatment. Participants therefore stressed the importance of educating professionals, as well as their own families, friends and their communities at large about the fact that the symptoms of FM are truly real and can be debilitating, hoping that such education would lead to a greater acknowledgment
and understanding of the condition. One participant said, "I want people to really acknowledge it exists because there is a stigma. I see it in the medical profession, and people on the street; they kind of think that people are lazy or something or they are just whining about something." Another participant further explained:

I’d like to see more understanding and also far more knowledge. Even if they don’t know where it comes from, or how, but a lot of learning needs to go on. It is very important for people to stop judging other people because they can’t understand. I don’t judge people and I don’t expect them to judge me because they can’t see. So don’t judge but become an informed human being.

Participants stated that they hoped increased awareness of the condition would enable doctors to make quicker diagnosis of other patients who develop the condition and would enable health care professionals to provide better care to people with FM. One participant shared her perspective as follows:

People need to know about this. Apparently there are 60,000 of us in this province according to the Fibromyalgia Society literature. People who do not know what’s going on with themselves or don’t have any help, so the more people know, especially nurses, the first line of defense in the hospital can help the patient get through a hospital stay. For me personally my worse nightmare would be going into a hospital for something else and having to explain all about my FM, why I can’t sleep, whatever’s happening with me as well as whatever’s going on that put me in the hospital. So if nurses were aware of how to deal with people with this, that would be a great help.

Another participant confirmed this, saying

It seems to me that nurses are more aware of fibromyalgia than doctors are. So I think, fibromyalgia should become part of the standard illness that a doctor needs to look at for a general practitioner. I think it should become a part of their curriculum.... I think it’s important because a physical doctor, you know medical practitioner, is the first person who deals at the front lines and unfortunately every time I’ve heard any story on fibromyalgia, each of the times and most of them females were told they had psychological problems, or mental problem or menopausal problem or a husband problem. And I think that our doctors ought to be more educated so I think it should be part of their process of learning to become a doctor that both fibromyalgia and chronic fatigue actually exists in our real conditions.
Finally, most participants also mentioned that it is important for others, especially health care providers, to acknowledge not only the physical, but also the emotional, psychological, social and other aspects of FM. One participant shared her perspective:

Ah...this condition [FM] is a physical condition. It becomes a mental health problem...not a problem but a condition that you have to work very hard at because it affects your emotion, your psychological well being. People pull away and it sets up other mental health issues so I think you have to look at the whole person and fibromyalgia in particularly is a whole person perspective. It's psychologically, it's emotionally, it's physically. And there's a lot of loss.... I think people who treat fibromyalgia has [sic] to start looking that it also affects the mental health and the well-being.

From participants' accounts and anecdotes, it was evident that they believed the invisible nature of the symptoms and the lack of objective diagnostic criteria had increased the odds of people with FM being discredited by the health care professionals and others. While this section discusses how the invisibility of symptoms affected patients' relationships with their providers, this invisibility also affected their relationships with families, friends and the others in their lives, a point that will be discussed later in this chapter.

Participants in this study alluded frequently to the fact that it is not their FM symptoms alone that create the emotionally stressful effects of the condition on their daily lives. They point out that along with the physical unpleasantness of FM symptoms, they suffer because symptoms of one kind or another are oppressively, unremittingly present in their lives, and because the varying and unpredictable nature of the symptoms keeps them off-balance and emotionally stressed. All participants were emphatic in stating that it was important for others not to be judgmental, but to show greater understanding and acknowledgment of fibromyalgia through a willingness to learn more about the condition. Participants also mentioned it was important especially for health
care professionals to look beyond the physical biomedical explanation for the symptoms of FM but instead to acknowledge the emotional and psychological effects of the condition.

Living with the Impact of the Symptoms

According to the participants, the symptoms they experience work together in a vicious circle that adversely affects their lives in various ways. Participants described in detail the impact of FM on their familial and social relationships and on their career and recreational lives. In addition, they noted the significant economic impact of FM because of the limitations their condition placed on their ability to work.

Familial & Social Relationships

Every participant mentioned that FM had a significant impact on family interactions and on other social relationships. One informant stated that the additional strains and demands brought about by the consequences of FM caused the break-up of her marriage. The other participants all reported that it took time for their families to understand and accept their conditions. Only one retired participant in this study, whose children had grown up and moved away from home, recounted that because her family placed the illness in a spiritual context, they became stronger and more connected as they grew together through the experience. Such comments of positive nature about the effects of FM were infrequent among the study participants, however. Most of the participants' comments pertained to the limitations the condition placed on their lives.

Participants found FM to be so debilitating that it affected their abilities to carry out certain basic activities of daily living. For example, they noted that they invariably had to relinquish several of their former roles. This required their spouses, partners or
other family members to take over many of the household chores such as cooking meals, buying and carrying heavy groceries, house cleaning, among other things that the participants were no longer able to accomplish. All of this created increased stress and strain on their loved ones. One participant recounted some of the additional functions her husband had to assume:

My husband did an awful lot of the lifting, helping me out of my coat, opening doors and things like that. They have heavy doors in all the stores and even the car doors are heavy. All of those things bother me.

Many participants remarked that family members often resented the additional burden of domestic work they were asked to assume, and noted that teenagers and children were particularly likely to complain or to refuse altogether to take on extra chores. The impact on the families seemed to depend on the developmental stage of the family unit and the availability of the family’s support system. One participant who is a single parent mentioned that initially her son was very angry with her about her illness since, as he was her only family member and support—she being a single parent with no other family in the city—he was expected to assume the household roles his mother could no longer fulfill. This participant shared the following perceptions:

It’s been very difficult for my son who just turned 18 to deal with my illness. He was young when I got ill, and he was helpful for a while. But he’s also a typical child. He had to carry a lot of groceries, he had to do a lot of laundry work, you know, lifting and helping and he had to...when I had been very active he had to all of a sudden accept that I couldn’t do what I used to do. And to his detriment he’s put on weight. He’s put on a lot of weight. He’s considered overweight now. He went from being a skinny little kid to...when I first got sick and I had to change the way we did our activities and the level, and I had to change my meal preparation because I couldn’t lift a pot on the stove...it’s my greatest upset in this whole thing. He had to suffer this because of my illness. And he resents some of my problems and that’s totally okay. And I got him through high school; he’s been a good boy and he hasn’t given me a lot of trouble, but on an emotional level it has been very difficult.
Another participant with teenage children described how her illness affected her family dynamics. Her children were going through their teenage years when she was afflicted with FM, and they were angry and frightened with the transitions brought about by the illness. Her husband was busy with his career, and there were no other supports or resources to help her family deal with the situation. All these additional stressors caused her family to break up. This participant stated:

I can't walk, I can't talk, I can't think, I can't cook, I can't care for my children....
My husband was distancing himself from me because he was really afraid of me. And it took a couple of years. I finally felt it was okay to let go but not to divorce....my husband didn't have the time to take care of them, he was very busy working. The kids you know, were so afraid of me, they were growing up. Like they didn't want to be in the house with me because they were also frightened and angry. Very angry. My oldest daughter started showing terrible signs of problems—not severe problems, but you know like there was a lot of anger. And I realize that I'm the only parent to her because my husband is not her father, so basically she was frightened. So she turned that into anger towards me and towards her step-dad for not being there enough.

Only two participants in this study stated that they had either an understanding family or supportive spouses. One of the two participants said:

Well, I have been very fortunate in my two girls and my husband because they've understood my condition, what fibromyalgia is. I had everything of "what is fibromyalgia?" And I had them read it. And all things I could experience at one time or another...

Though there were educational pamphlets and programs available to inform and counsel family members about FM, most of the participants mentioned that their families refused to go for counseling or education in order to understand FM better. One participant said:

So while you can try that and there may be some enlightenment of some family members who are open to learning [about FM], you'll find a lot of them will not be able or will not want to go. So I think it's difficult to bring family members into the process. And it takes a great deal of understanding between the people within the household. And I think teenagers and especially younger kids— preteens and teens,—they can't be bothered because they have just been exploring this huge brand new life and they're far too selfish to even want to deal with it...
Teenagers are a little out of order most of the times so they certainly don’t want to deal with a lot of that because they are too busy doing their own thing.

According to the participants, it would have been difficult for family members to understand and be supportive even if they had been to educational sessions on FM, as they had their own individual needs that had to be met. One participant explained:

My son actually came to the Arthritis Society’s fibromyalgia program. I think it was six or ten weeks long, I forget. He actually came to the sessions in that family were allowed to come and even though it was related to him and he was ten or twelve at the time, you know he still has a problem understanding what I’m going through. Just like anybody else. You know. I understand why he is upset but I wish he were more sympathetic. And he has been educated on the information. You know. He has access to it; I keep nothing from him...you know. When things are bad I tell him but it still...there’s still that upset, you know. “I can’t do this and I can’t do that” and maybe one day I have to break a plan or “No, I can’t sit in the car for an hour today and drive you around.” You know just...maybe parents go through this especially in teenagers all the time but I find a lot of our disagreements are based on my health. You know, because I can’t do something or I don’t feel up to honoring a commitment. It’s difficult.

As this participant’s remarks suggest, in addition to the shift in familial roles, one of the effects of FM on the sufferers’ lives is that they are often unable to do the things they want and need to do, both for themselves and for their families. Participants reported that they could not keep up with their previous levels of social commitment to their families and friends. For example, they would plan as best as they could for social events only to find themselves having to cancel appointments at the last minute due to extreme pain or fatigue that was a disappointment for them and their families. One participant recounted such a frustrating experience of having to forego a family get-together at the last minute:

I can see how fibromyalgia has interfered with relationships. I haven’t...we haven’t lost friends but it interferes with relationships [pause] what you would do at the spur of the moment, spontaneously, or you’d make a plan to go someplace as a foursome and then... I end up having to cancel out not a few days ahead but an hour before and only by grace of God, that these people being so
compassionate and would understand. This has happened with my [spouse] and I. You know...we’d be ready to go for a dinner—$50.00 each...for each ticket. It comes...the day comes and we get into the car... and I’m feeling terrible.... I just get back into the apartment, lie on the couch and just drop. But angry at the same time. Because I see what it’s done to me.

The only participant in this study who was both working and going to school mentioned that sometimes, in order to protect herself from intense flare-ups of symptoms and to preserve her energy for the important priorities in her life, she had to forego her social commitments to her family. This participant said:

I am usually pretty good at following through what I promised to my kids, but it happened on some days when it has been really bad, and I am just not able to take them where they want to go. It’s just too stressful on me or it hurts too much, so I will say no to social situations when those are easy to say no to.

Not only has FM had an impact on familial relationships, but participants also reported that their relationships with friends were affected. Unlike one participant who had understanding friends, other informants stated that they had lost many friends due to the unpredictability of their symptoms—something that hindered their abilities to keep social commitments. One participant mentioned how she had to cancel her appointment with her friend at the last minute due to pain:

Last month I was supposed to go to Playhouse Theatre and I gave my ticket away because I had too much pain and I just thought I can’t sit there. Well it’s upsetting and rather disconcerting because my girlfriend had just come back from Hawaii. She had missed the last month and this was going to be our time together ‘cause we go to dinner afterwards. But I couldn’t go. I just couldn’t make it.

Participants stated that it was difficult for their friends to understand why they looked well outwardly and yet did not have the energy to always follow through on their commitments to social functions. One participant said:

As far as relationships with other people, the only thing I’ve found is that people have you out to dinner and they don’t understand when you do not reciprocate. They think like all my friends say, “well everybody has something wrong with
them; you can put on a dinner, or a luncheon for 10 girls.” You know, I don’t argue with them, I don’t say anything. I find that by the time I prepare things and get things all ready, I don’t know whether I’ll be able to serve it because of my hands. I can’t lift and I ache so bad that I’m in a mess.

Because of this lack of full understanding from their friends, most participants were careful not to talk too much about their illness and pain to their friends, since they believed that most friends want to do social “fun” things together and not listen to their continual descriptions of being in pain and suffering. Most friends could not fully understand and empathize with someone in constant pain. One participant said:

You have to be somewhat careful of how you talk to your friends, how much you reveal of what’s going on or else you tend to be talking too negatively about too many things. When I am in bad shape particularly, ah, I feel that I need to hide a fair amount of that or bring the general level of energy down. I have lost many people when I was in really bad shape... quite close friends, who actually said, “I can’t take this. I can’t stand being around you.”

In order to avoid being stigmatized, “judged” or “seen in a bad light” by their friends, most participants chose to isolate themselves socially, not openly disclosing the daily struggles they were having and not allowing others to see them looking miserable due to the pain. One participant shared her perspective:

I find myself reluctant to share the reality of my life with very many people. I don’t want to be seen as a basket case. I tend to shun the company of others when I am in really bad shape. When I know I am about to “crash”, I will do almost anything possible to make it to a private place before I fall apart. That means few people see me when I am at my worst. Part of my reason for keeping things this way is pride, but part of it is a lesson learned the hard way—I have lost close friends who left saying, “I can’t stand seeing you in so much pain. It’s too hard.”

Nonetheless, most participants stated that they tried to deal with the FM themselves in order not to overburden their friends who have their own life struggles to deal with. One participant said that he knew others were concerned when they asked how he was doing and his response was:
I'm taking a day at a time. I don't go into details. Otherwise if I start unloading on them, it's...I'm not saying they're not interested, but I don't know what they're dealing with either. What issues?

In response to the reactions of those around them, participants mentioned that they reduced their social contact to a small circle of friends who were understanding and supportive of their condition. Even with such a limited support network, this study's participants would often try to keep their suffering to themselves and isolate themselves in order to avoid adding to the burdens experienced by others who had their own life issues and difficulties to confront. Accordingly, when participants isolated themselves in this way it prevented them from getting needed emotional and mental support.

Career and Recreational Impact

In this study, five of the eight participants had stopped working altogether and were on disability, one was retired, living on her pension income, and one was doing occasional casual work. The only participant who was still working mentioned that she was able to keep doing so because the hours were flexible and she could work at her own time and pace.

The five participants who were on disability reported they were still working when they were first diagnosed with FM; gradually, they had to switch to part-time hours and finally to stop working altogether due to the incapacitating effects of FM. These five participants reported that during the time they were still working they had to forego social, recreational and other activities in order to conserve their energy for their work, which was the high priority. All measures were taken to help their bodies recuperate sufficiently to allow them to return to work again. One participant recounted:

But until that point where I stopped working, I'd spent the two years icing myself down in the morning, getting up an hour earlier to take medication to see if I
could get up and go to work. On my feet all day. The horrible pain. Getting home, everything I did outside of work was to try to get me in shape for the next day's work.

According to the participants, it was not only the pain and fatigue that hindered them from functioning at the level necessary to keep up with the demands of their job; they also found it hard to sit or stand for prolonged periods, or to do work involving a lot of repetitive movements. As one participant explained:

I had to really say how limiting fibromyalgia is. I couldn't be able to commit myself to work every day. To find a job that you wouldn't have to show up everyday and you wouldn't have to do longer hours. I don't know how long it's going to take me to actually find a job that I can actually do, as I haven't been able to sit long enough.

Even doing part time work or casual work can be difficult. One participant said

My contract is over. I have done the work. It is clear it will take my body some time to recuperate. I do not know how much time, but I am familiar from the long haul of rehabilitation with what I must do to help myself. I will do those things, and I will pause to breathe before looking for more work.

Sedentary work involving a great deal of concentration, the processing of information, and the learning of new skills also posed challenges for participants. One participant described the problems she would face like this:

Volunteering or working part time, trying to get into something is good but it's difficult. It's difficult because like with fibromyalgia I found my concentration abilities have diminished considerably to be able to sustain something for any length of time.

Participants stated that mental cloudiness and their physical symptoms interfered greatly with their job performance, and they suffered frustration and shame as a result. As one participant said:

I cannot do my former job, and I haven't found one I can do yet, and I wish part of my acuity and learning and memory were given back to me. That means that I could retrain as something else. It is tragic to lose a functioning life like that, you know, and not feel that you can relearn anything or be retrained in anything. You
know, aside from the physical, it's difficult for a person who had a good life and a
good job to not be able to do those anymore. I wish that there were something that
I could do within my limited sphere now. Who would hire a person like me? I
would be unreliable as far as attendance. I would be difficult to train, I might
spend half my workday in the washroom; or the other half having a fatigue spell
in that I cannot raise my head. Who hires somebody like that? And how do you
teach a whole new job cause; even the simplest McDonalds position you're
required to learn a lot of things.... You know so how is an employer going to
teach me a new job when I can't do my old one. And even physically if I could,
my mind is gone.

Participants stated that not only did FM itself affect their concentration and physical
performance, but that treatments for their symptoms often caused them difficulty as well.
For example, some medications affected their mental functioning, compounding the
“fibro fog” effect. One participant said, “I got to the point where I was taking so much
medications for pain that it affected my memory, cognition and calculating functions in
my brain.”

The management of FM has required frequent visits to physicians for this study’s
participants, which made working at a regular job difficult. Few participants had
sufficient flexibility to allow for such time off; eventually, in any case, the physical
effects of the symptoms were too great for most participants to continue to work. One
participant said:

My health and the hours of standing, you know, and I was starting to work 5-6
days a week because I was having many medical appointments and I would lose
time so they would let me work other hours that I was happy to do when I could.
And then I started spending all this time in the washroom with the irritable bowel
and it got to the point one day, I bent down to pick up either the laundry or clean
the kitty litter, and I see stuff and I could not move. And that was the time my
doctor said you have to stop working.

All participants mentioned that they would like to contribute to the workforce but
society’s work-system is such that most employers would not want to hire someone who
was not sufficiently “productive” or “marketable”. It was hard for the workplace to easily
accommodate flexible working hours for people with FM. One participant recounted her experience as follows:

Well...because I guess the workplace...they have expectations and they're not willing to say, “Okay, well, then if you phone in and say I can come in for 4-hours today,” most workplaces don't function like that and so it creates a problem. I mean our society is for the most part 9 to 5 and...no, it's beginning to be 24 hours but I mean...it is...and it's sort of left, I think, to the worker to get someone to replace them if they can't do something or if they are at work and all of a sudden they can't concentrate on whatever they're doing to either force themselves to do it and then become extremely fatigue and then they're out...off work for the next few days because they're so tired that they lie in bed and they are in pain. And I think that the other aspect too is of course people with fibromyalgia don't look like there's anything wrong with them.

This comment also alludes to the fact that even if there is some flexibility in the workplace that might allow for time off when symptoms are severe, many employers suspect malingering when the employee asking for time off looks healthy. Yet all participants mentioned that they would have liked to be able to be employed if given the opportunity, or to engage in job retraining, or work in a job that could be especially set up with a flexible schedule. One participant shared:

One thing I've thought of is being able to have a part time job, because I don't think I would ever be able to work full time but it depends of course on the job too. Maybe a job that you had a little bit of your own autonomy in your schedule so that you know you could leave it and pick it up again, depending on how you feel. That seems like a bit pie-in-the-sky type of thinking but I don't know how else you can do that because you can't be relied upon to be able to be there.

Most of the informants in this study stated that they felt uncomfortable when others around them asked them the common social question, “What do you do?” Because they tended to look well, it was hard to explain to others that they were incapable of working due to the many limitations imposed by FM. As one participant noted, “There is a stigma attached; the first thing that comes out of people’s mouths is ‘what do you do, what is your work?’ Oh, I don’t work or I have a disability. You are a cast-off.”
Many participants expressed a feeling of guilt and a lowering of self-esteem because they had to collect disability income or were no longer able to contribute productively to society. One participant said:

I am on Ministry disability benefits, that provides me with no status whatsoever and an income that is insufficient to live on. Strangers commonly ask me, “What do you do?” When they find out I receive disability, they often sniff, “You look all right to me. I don’t think there’s anything wrong with you.”

Another participant commented:

You know you go to church and they talk about their work and things like that. Well, I’m no longer talking about my work. And I start wondering, “Well, you know, it would be nice to be productive.” And I become fearful wondering, “Well maybe I’m never going to be able to work again.” Maybe I’ll never be able to do anything...that hurts inside. I guess a person doesn’t like to have the label “you’re disabled.”

Another participant felt very strongly that having a career was the only thing that gave her a sense of fulfillment and achievement in society, saying:

Most of my energy is used up by the activities of daily living, self-care, housework, grocery shopping, meal production, laundry, chores etc- activities that are necessary but leave me with no sense of accomplishment. In the larger world, no one is impressed by how well I take care of myself, my household and my daughter, no matter how well I do it. Neither are people impressed by the volunteer work I do. Those are not activities that gain me any recognition or status. I miss the status.

Participants said that in some cases, even if they wanted to work, they had to be careful not to increase the difficulties they would face should they need to apply for disability benefits in future should they “crash” from increased fatigue pain or fatigue from their job. One participant shared, “I was offered a teaching job...teaching Nurses’ Aides, but it was full time and I went to my doctor and he said, ‘If you do that within a week you will be crashed and then you’ll have to fight to get your disability again.’ While the participants wanted to be productive in terms of their sense of accomplishment and self-
Esteem, they also reported that they were thankful that they were not working, for they recognized that they were "not able to function" nor fit into the "pressure of a regular work schedule." They explained that they needed to not work so they would have the flexibility to pace their daily activities according to their limitations and energy level.

One participant said:

I am so grateful that my life has the flexibility, now that I'm not working, that when I crash like that I can stop and I can rest. I can do the things I need to do to look after myself. If I just stop and rest, I can recover in a few days now, instead of weeks or months that it previously took me to put myself together, but it's still very difficult to accept how easily I seem to crash.

The married participants had to rely mainly on their spouses to be the major breadwinners, but they attempted to help with the household chores as much as they could. As one participant commented, "My [spouse] is working full time and I'm at home full time. So, trying my best to offset, I try to make some meals, like trying to do some of the cleanup."

Not being able to work affected the monetary resources that participants had available for leisure and recreation. One participant said:

Yeah, and as far as a social life it [FM] really does impinge on that. Well, being off work with the fibromyalgia and the injuries, now there's only a limited amount that you get for your monthly stipend so that also affects what I can do.

Participants also made the unwelcome discovery that the activities that used to bring them pleasure and fun had become a strain. One participant had planned an enjoyable outing, but the outcome was not what she had planned:

This weekend was to be an exception. I went to a one-day journal workshop with a great group of women, but I conveniently forgot that recreation also requires an outlay of energy. By mid-morning I was in great pain. By noon it was difficult to concentrate and to write.

Another participant stated:
Fibromyalgia impacted my life measurably and considerably. It has changed a lot of things for me. There’s a time when I was very athletic. I loved playing tennis. I loved to golf. My [spouse] and I loved to dance. Ballroom dancing, Latin dance, and we would go out two-three times a week a couple of hours each. That’s gone! I haven’t played tennis for years. The last four years. Golf. I went out maybe two years ago and almost couldn’t complete a round of golf...on a small course. It wasn’t one of these major courses, just a small course. A Par Three course. And I found that painful and just about couldn’t do the whole walk.

The many accounts of the losses participants have suffered because of FM reveal one of the very difficult aspects of living with FM: the blow to the FM sufferer’s sense of self as a useful and contributing member of society and his or her family. Another important aspect of the loss of self-esteem is the inability of someone with FM to continue taking part in other recreational and domestic activities (besides work) that help to define the self, and that provide meaning, purpose, and pleasure. Participants found these losses and the emotional consequences for themselves and their families to be a frustrating and demoralizing experience.

The Economic Impact of FM

Being unable to work created great financial strain for the people with fibromyalgia in this study. Only one participant was working on a casual basis; one had retired and had an adequate pension income; the other six participants were on disability.

All the participants in this study who are not able to work stated that the many bureaucratic procedures to get disability benefits created additional stress for them. They attributed these difficulties to, on the one hand, the tendency of health professionals and disability bureaucrats not to consider a diagnosis of FM to be a legitimate illness, and on the other hand, to the current political and social context (in which both health care and social services are under tight budget constraints imposed by both the provincial and federal governments). One participant said, “It is a problem, if you have an invisible
disability, how to identify yourself as someone with special needs.” Another participant remarked, “It was hard to prove I’m unable to work because I don’t have anything in the way of visual photographs or X-rays or a blood test or all that sort of stuff.” She said, further, that having to constantly prove that she was sick to get her disability going was an extremely stressful process.

According to the participants, some physicians did not acknowledge the condition and were hesitant to sign disability papers for them. It made a tremendous difference, according to the participants, if they had physicians who were “willing to stand behind us and fill out some of the forms.” The informants expressed fear that the government might cut off or curtail their disability benefits. Some participants had family members who could help, but some were single parents or unmarried and did not have family support.

One participant recounted:

I have insecurity, as I fear that LTD may be withdrawn at any time and what would I do...living in a dumpster? In the first several months of collecting LTD I had to reconcile to the possibility that I may have to sell my condo and move to a cheaper apartment. To date, with financial assistance from my parents and strict budgeting I’ve not had to sell, but the concern is always before me.

Some had to repeatedly fight for disability allowances. One participant described facing the difficulty of having to fight for her benefits as follows:

I qualified for the Canada Pension for disabled. I qualified for the provincial and here am I having to fight for the provincial again. If I was employable, I’d be out there. But I have trouble learning new things; I have trouble retaining things. I have trouble standing and sitting. I’m unmarketable. But it would be nice if the government would decide. Instead of me having to fight for it all the time.

This financial difficulty presented participants living with FM with additional problems and stresses with which to cope. An example of one such additional economic burden is the cost of medications. Participants stated that they had to use conventional medications
plus a combination of alternative therapies to mitigate their symptoms, and most of the alternative therapies were either minimally covered or not covered at all by the Medical Services Plan. Therefore, financial constraints forced many participants to make cost-based decisions as to which treatment option to choose rather than decisions based on treatment effectiveness:

The first real relief I had from the nearly constant pain was in 1997 when my chiropractor started using a technique he called neural injection therapy. This involved injecting an anesthetic, lidocaine, along with a homeopathic remedy for stress, directly into some of my trigger points. This was not covered by the Medical Services Plan, however, so I was able to avail myself of it only infrequently. This chiropractor used acupuncture sometimes as well, that was also very helpful, but he charged a lot for it. Eventually I decided that acupuncture was giving me the most relief so that is where I presently concentrate what financial resources I have. I found a Chinese practitioner who gives me one-hour treatment for the cost I used to pay to the chiropractor for five minutes of treatment.

Though participants were aware of the benefits of engaging in regular aerobic exercise, and of making frequent visits to the physiotherapists or massage therapists for alleviation of their symptoms, they also pointed out that they were unable to pay the necessary fees to access these treatments on a regular basis. This often created problems as some treatments need a regular pattern of administration in order to be effective. As one participant commented:

For my body, none of these treatments work unless they are done regularly. Massage for example is very helpful if I get it on a regular basis, but if I scrounge the money for a treatment here and there, it will often make me worse, just stirring up muscle spasms without resolving them.

One participant said that she was thankful for good church friends and families who helped pay for some of these expenses. Two participants were single parents with no immediate family support and they recounted that it was a struggle for them trying to make ends meet and to access medical services on their meager government assisted
welfare income. All the participants said that they wished the government would acknowledge the condition and grant them better coverage for various treatment modalities such as visits to the massage therapists or physiotherapists. One participant further mentioned the importance of setting up a political group to lobby the government:

I think that we need a political body behind this disease or this condition so that we can actively work as a group to make a difference... One of the things I wanted to say is that I find very discriminating from this government, the only thing that helped me tremendously was massage therapy. And this government took away massage therapy so that left me without any form of massage therapy, and it is well documented that massage therapy is one of the best therapies with fibromyalgia, and that means to keep those muscles supple enough so that we continue to be productive members and it's only at a very small cost to the government...

One participant described her sense of injustice given the conditions most people with FM must live with at present:

I will keep believing that somewhere, sometime, people with disability will be able to stop ricocheting between poverty and jobs that are too much for our bodies to handle. I will keep believing that somewhere, sometime, in recognition that the contributions we have to make are worthwhile and worth paying for, work places will be truly accessible.

Despite this participant's hope for improvement in the future, informants perceive their current reality as lacking in adequate financial and social support. Repeatedly, they described their feelings of devastation as they had to endure their FM within the political and economic context of the surrounding society that shapes their experience of living with FM.

Management of FM

Because FM's symptoms are so random, variable, and unremitting, the participants in this study felt they had to take an active role in adjusting to their illness. In general, the strategies they used to cope with FM involved considerable self-awareness
and careful self-management of their condition on an ongoing basis. First, the participants had to decide upon a basic attitudinal strategy: they began by asking themselves what attitude they would bring to the task of managing fibromyalgia, and how they would maintain it over time? Then, in dealing with their symptoms, the participants found that they needed to master the difficult art of finding and maintaining a balance of trade-offs to minimize the symptoms without creating undesirable side effects. This process involved learning to combine various therapies including conventional medicines, exercise, comfort measures, alternative therapies. Managing from day to day also meant modifying daily activities and routines. In addition, participants sought and used support networks including formal or Internet support groups. They found it helpful to develop and maintain close relationships with their health care providers. Finally, participants noted that despite their symptoms, they felt that it was essential to engage in ongoing attempts to be productive.

Use of Attitudinal Strategies

Participants recounted that they had to acknowledge and integrate FM as part of their lives and to accept the fact that they could no longer continue with many activities in which they had previously engaged. They had to learn to live within the boundaries brought about by their condition, adopt changed attitudes, and adjust to a new way of life. One participant explained:

I think a very important thing for a person to learn and to accept about this condition, in respect of themselves, is that you must give yourself permission for your limitations. You cannot always have a spotless, clean house, you cannot always keep your commitments, you have to understand that you do what you can do when you can do it, and to not feel guilty when you can’t do something. I think people are unusually hard on themselves with this condition and they have to literally give themselves permission to stop activities that are going to hurt them or flare-up their bodies....You do have to learn to cut stresses out of your
life because this is also a stress activated condition.... Because there’s no way to keep up that kind of life with this kind of condition. You have to readjust, you lose a lot and maybe that’s where the despair and the depression come in because you will lose a lot. You cannot keep up to a normal life. But you have to not be hard on yourself.

Although FM had limited their daily lives in many ways, and they sometimes felt angry, frustrated or depressed, all participants emphasized the importance of maintaining a positive attitude as a vital strategy in helping to manage the condition. Four of the eight participants in this study were Christians, and they reported that they prayed and drew their strength from God to cope with the condition. One participant said:

I do sometimes feel depressed on some days, but God has blessed me because I believe. And I can take a positive attitude. And that helps me to overcome any depression that I would feel because, if this is my thorn in my side, I will suffer it.

Yoga, meditation and counseling were strategies that other participants adopted.

Since the participants woke up daily to the same struggles of pain and fatigue that nothing seemed to change, they admitted that their abilities to influence their attitudes varied from day to day. Most participants tried to use cognitive strategies, such as telling themselves that things could be worse, or that other people might have more difficult things to deal with in their lives than they did. One participant further explained the attitude she adopted to look at her own FM:

The whole thing with this illness is you learn very quickly that it will not necessarily cut your life shorter. You get to wake up miserable every day but at least you get to wake up. There are many people who get illnesses, cancers and things where they die in accidents and some days you might pray you had something fast that takes you, but most days you just consider yourself fortunate that you get to wake up in the morning...you get to see your children, your family and the sunshine and many people don’t get that opportunity. So if you have to look at it that way, at least you’re not going to die in six months, you know, from some fast ravaging cancer or lingering disease. You get to live, but you get to be challenged while you live. And you have to accept that too.
Though most times the participants acknowledged and accepted the limitations of their condition and tried to maintain a positive attitude in order to effectively cope with it, they stated that they did not always readily accept the condition as part of their lives. One participant strongly expressed her contrasting perspective that, although she acknowledged the presence of the condition in her life, she nevertheless considered it a defeat to fully accept the limitations of the condition:

Desperately, I don’t want this condition! But if I’m going to live with it, I am going to fight it every inch of the way. I see it as my enemy and I am not going to accept it. I accept the term fibromyalgia. I accept the reality of the pain. But I’m not going to accept that this is going to be the part of me for the rest of my life. Whether it is or not, I’m not going to do it because to me if I accept, that means defeat… I do not accept defeat. I accept that I’m ill; I accept that I have a condition, but I am not going to accept defeat.

All the participants stated that they were still trying to maintain hope for a miracle cure one day, or at least a treatment that would give them adequate relief of their symptoms. One participant said:

That is my fondest dream! If they could figure out a way to cope with my pain, and not knock me out so totally that I have no quality of life. There’s a great price to pay if you want almost total pain relief; you’re in a stupor. You cannot function. I want better pain relief and I want to be able to function and that’s what medicine needs to find out for me.

To summarize, participants stated that while they did not welcome the presence of FM in their lives, they had to adjust their attitudes and learn to live with the condition while they had it. Reframing their minds with positive attitudes seemed to be a helpful strategy used by the participants as a means of coping with FM.

*Trying to Find and Maintain a Balance*

Besides having to give up their old way of life and adopt attitudinal strategies, the participants in this study reported that trying to find and maintain a balance was a large
component of managing their FM. This involved the art of making decisions in a variety of areas. For example, they considered when to use conventional medicines and whether to exercise, or use comfort measures or other therapies or a combination of these. As well, they continually evaluated to what extent their needed to modify their daily activities and routines to best manage their symptoms.

Use of Conventional Medicines and Exercise

All the participants used conventional medicines to assist with the management of their symptoms. Some of the medications used by the participants in this study were Advil®, Tylenol®, and codeine-containing drugs as pain relievers and Flexeril® and Neurontin® for muscle relaxants and also as additional pain relievers. Elavil® was used by most participants in this study to help with their sleep. Some participants used Cytotec® and Losec® in addition to regulating their diets to relieve irritable bowel syndrome. But these medicines did not always work; as one participant said, “Pain medications help some days and some days not at all; you can only hope.” There is considerable variation in the effectiveness of medications in alleviating FM symptoms. Just because a medicine worked for one person with FM did not mean that it would work for all. As an example, Neurontin® and Flexeril® provided pain relief for some participants, while others complained of unpleasant side effects from using them. One participant said, “Sleep meds have been a huge problem finding the right one, hoping it lets you reach restorative sleep yet doesn’t tire you in the morning.” This same participant further mentioned another dilemma she encountered: “As far as the pain medications they cause side effects with the irritable bowel syndrome because the codeine slows the gut.”
Participants mentioned that “it’s a fine line trying to control the symptoms,” and it is also a “balancing act” trying to decide how to best deal with them. On the one hand, participants had to decide whether to take medications to relieve their symptoms in order to have a functional life while knowing, on the other hand, that the side effects of some of these medications might augment their other symptoms. One participant described that, in order to have a reasonable functional life, she decided to take the medications and bear with their side effects:

I know many people with this condition who don’t get out of bed on a regular basis. I try to get out of bed every day regardless of how I feel. I’m trying to function so I take the various medications, the anti-inflammatories for the muscles, for the pain in the hopes that while it causes other problems it will at least allow me to continue to have a life.

Another participant elaborated on this juggling act of trying to maintain a balance between using medications to mitigate the symptoms, and enduring the symptoms to avoid side effects of the medications:

That’s true about the side effects that some medications can have. Dryness, dizziness, dry mouth...that’s what I mean by dryness. Dizziness, fatigue, those are...maybe a sense of disorientation...that’s an interesting...it’s interesting because one has to wonder. “Gosh, I feel so fatigued.” Is it because of the fibromyalgia or is it because of the medications that you’re taking. But the vicious circle part is, “Okay, I won’t take the medications and then I’m dealing with the pain now.” So I take the medications and I just have to deal with the side effect. That’s where the physician comes in and that’s where the patient has to make it clear. I’ve taken a medication to help me sleep at night because unless you get that much needed restored quality sleep, life is just...life is not good. The whole idea is to get into a state of restorative sleep where your muscles have a chance to recover and to recuperate and to restore themselves so that you feel revitalized the next day.

At other times participants decided not to take medications in order to avoid having the side effects pervade their lives. One participant shared

You have to determine in your own right whether or not, with this pain, do you want to take medication. I’m choosing not to take medication. I want to know the
boundaries of my pain because it helps me understand what I can do, and when I can do it, and could there be a better way. I think some people will do something regardless of the pain and take medication to take away the pain and then do it. I do the opposite. I say, “Okay this is causing me pain so how can I find another way around to do the same thing.”

Besides using medications, participants found it necessary to engage in some form of aerobic or low-impact relaxation exercises, but as one observed: “You see, you can’t go to ordinary exercise classes. Because I think that they are too advanced for what we can do. You’d have to go at your own pace.” Given the erratic nature of FM symptoms, participants found it hard to gauge their physical limits when taking exercise; what was considered reasonable exercise on one day might be too much on other days. One participant explained:

One of the things I find baffling about my condition is that no matter how regularly I exercise, my system does not seem to adjust to my activity level. Though I keep to a regular schedule, after every exercise session, my body reacts as if I have just overdone things after a long period of inactivity.... It is a constant battle for me to keep to my exercise schedule. For one thing I want to do more than I do. I miss the endorphin rush of more vigorous activities. For another thing, there are some days when after I have exercised I am unable to do much of anything else for the rest of the day. It can be a hard choice to make.

Another participant made a similar observation:

There are days when I go on my exercise walks and I’ll walk quite briskly, feel pretty good. I generally feel pretty good when I’m done. There are days when I go on my walks and my legs will start to be cramping up. My knees will start feeling very, very sore and I’ll be halfway and be standing there on the street thinking, “I don’t know if I’m going to be able to finish this.” And yet, nothing has really changed during the week. So, yes! There are days...there are better days than others. My challenge is trying to be consistent. I would like to be able to go out and do a half-hour walk every day. There are times when I can’t get off the couch or I’m ready to go to bed and I just can’t get excited. There are other times when I have to force myself up. I literally force myself. I put on my shoes...I have pain doing that. I put on my coat and I say, “I’m going to do this...I must do this.” And I’m doing it for one reason... I know it’s going to help me. So it takes a lot of will power to do that. So I’m trying to find that balance of when I’m done, it’s been enjoyable rather than when I’m done, it’s been painful and difficult and, “I don’t want this anymore.” So I can understand other people saying they have to
pace themselves and there’s days when it’s just the pits for them and they just can’t go out.

Though participants knew the importance of exercise, they found it difficult to engage in exercise regularly because it often caused worsening of symptoms. They admitted that often they had to will themselves to do things they wanted to avoid because of constant pain and fatigue.

*Other Comfort Measures and Alternative Therapies*

As most conventional medications did not seem entirely effective for many of the symptoms of FM, all participants also turned to various alternative therapies. These included visits to massage therapists, acupuncturists, chiropractors, naturopaths, and herbalists. In addition, participants in this study tried to avoid the unwanted side effects associated with an excessive usage of medications by experimenting with various comfort measures to aid with symptom management. In all cases, participants aimed to balance the conventional medications they needed with a range of alternatives that they found helpful. As one informant noted:

I find it tremendously hard to take painkillers because it makes you like on a high and I can’t live on a high for the rest of my life. And so, what I do is that I will take a half-hour shower and it’s two-fold. It loosens all the muscles depending on where I’m having the pain. Mostly it’s in the shoulders or the neck or the back and the arms. I will take a shower and because it makes me warm, it’s quite soothing. And it rests my mind and it also calms me down.

Another participant described using another method to deal with pain:

I have a wax therapy spa, a device that you melt maybe 6 to 8 inches of wax in this large container and after it’s all fairly melted you dip your hands in several times, put a little plastic bag over it and then a little mitten on it. I’ve done that with both hands, both feet, about 20 minutes later you remove the wrappings and peel the wax off, it comes off very smoothly and your hands just feel so wonderful. Feels so wonderful...my feet. If I were to stand up and stand on my feet it would bring relief. It’s odd and strange that it would bring relief. It would actually feel good.
Participants also used activities such as going for a walk, engaging in craft work, doing crossword puzzles, becoming involved in yoga and playing computer games, to distract them from dwelling on their pain. One participant said:

I don’t think there’s a time when you’re absolutely free of pain. And if you are busy and working in other interests you’re not feeling it at that point because your mind is on something else. But as soon as you sit quiet and you don’t have anything on your mind that’s when you will feel the pain again. It’s always there.

Another participant felt that expressing her emotions through craft helped:

The other part of pain that I have a problem with and I get angry about it! And I want to scream and I want to shout and I want to punch the windows out and I want to attack people and I have to be careful because the people are my children or somebody who can set me off because I’m now having anger battles going because I know that they can’t see, I know they can’t understand it, and it’s not a visible illness. So I rather say nothing, but I have to find a way to deal with the anger. I take very small objects to do. I like to make cards so I take some small project, do a tiny bit of cutting, do a little bit of gluing, do a little bit of, whatever I’m doing to make cards and just make the cards. Make something pretty when I’m at my worst and then I seem to feel it fades my anger as I focus on something that is beautiful. My anger goes out of the window, and sometimes I just ask God to help me through the day.

Most participants sought alternatives to conventional therapy in the quest for relief from symptoms without the side effects that accompany many of the usual medications prescribed for FM. However, participants noted that certain of these alternative therapies and comfort measures also had emotional and psychological benefits that made these an excellent choice for them at several levels.

**Modifying Daily Activities and Routines**

Participants unanimously reported that another means to maintain a balance in their lives was to modify their ways of carrying out their daily activities and routines.
They used shortcuts, found more creative ways of doing things, and paced their activities to avoid triggering increased pain or fatigue. As one participant commented:

You become an expert at the shortcut. If there’s a way to do something with expending less energy I’ve found it. I have just had to live my life by constantly thinking, “How much is this going to take, will I be able to do it, and then do something else.” What do I have to do to continue to function, not only to function but have quality of life with a child! You have to pace and you have to figure out the easiest and if you want to call it the laziest, that’s fine, but the laziest way to be, because this is a self-managed condition.

Another participant recounted how she creatively modified her ways of getting things done:

I find another way around to do the same thing. For example, moving pots, doing tasks where I have to bend or stretch. Stretching is very complicated and can be very painful to the neck so I use a stool. I can’t really scrub, so maybe I can sew something for somebody, and somebody could scrub my carpet when it has to be scrubbed.

In addition to finding shortcuts and creative ways of doing things to protect themselves from triggering increased pain or fatigue, participants have found that they had to plan their days carefully, parceling their energy and pacing out their activities accordingly. One participant said, “I try not to over-plan days. I’ll do just so many things in one day and then I’ll have to put the rest off until the next day, or the next day, depending on how much energy I’ve got back. So I do schedule around it.” Another participant elaborated on how she had to carefully plan and pace her activities each day:

I feel very restricted. Everyday I have to make decisions about how much I can do without setting off a flare of my symptoms or a general “crash.” A lot of my energy goes into mapping out how to get everything done, but the everything used to be the small stuff of life, things I used to just fit in whenever I had the time. Now it’s can I do the laundry? How about vacuuming the floor? If I have an appointment can I walk there or should I take the car? Is this a day I will be able to handle taking the bus? If I take the bus, what kind of shape will I be in when I get to my destination? If I have a meeting or a social function to attend in the evening, will I still be well enough to function properly at it if I do chores or errands during the day?
The participants described the need for flexibility with their plans, since they could never predict how they would feel ahead of time. One participant said:

You have to figure out how you're going to get through your day and it changes every day. There are days I have plans and I get up, and there will just be no activity that day. And it's not my choice. And there are other days when you don't feel good but then you have the energy. The pain might be high but you have the energy so you take advantage of that. Every day is different, and sometimes every hour and minute is different.

In their constant planning and pacing out of their activities, most participants reported that they found trying to figure out the limits of their energy and endurance to be a continuous process of trial and error. One participant said:

My life is a constant balancing act and despite the fact that I have had years of practice, I still keep making mistakes. When I overdo things, I suffer from pain, intense pain, an intensifying of some of my neurological symptoms, a flare-up of irritable bowel syndrome and a general feeling of being overwhelmed and unable to cope.

Most participants, however, considered the pain was manageable if they listened to the cues of their bodies, and did things in a certain way that expended less energy or "parceled out" their energy to deal with their daily tasks interspersed with periods of rest—measures that enabled them to cope with the day. All participants noted that good days, when the pain and fatigue were not as severe, were windows of opportunity to catch up with household chores or other activities they had deferred from bad days:

I'm able to do within the limitations that have been laid on me at this time. I'm able to find some activities... I mean... a lot of the things I'd like to do at a particular time I can't, so I have to... wait for that opportunity, you know, to do it and that's like... like I mentioned the bathroom... you know... cleaning it up and all those issues... day after day after day, so I figure, "Okay, how do I cope with this." Well, what I do is, okay, rather than do a whirlwind clean out like I would normally in a healthy state, I'll do a little bit. And try to figure out... I try not to push myself. Listening to myself has been important. "I've got to lie down." That's it. I crash! It doesn't matter what I'm doing, it doesn't matter what's involved and if I were at a dinner-dance with my wife and I needed to leave, she
would be very understanding about it, and I'd just have to go. I've got to shut it down. Rather than push myself. So that's helping me cope.

Though pacing of activities was necessary in their daily living, participants mentioned that on certain days and at certain times, even pacing their activities and careful planning did not help:

Planning and pacing can be useful at times. I conserve energy whenever possible. Problems can arise though when no matter how well you plan, the pain, fatigue or irritable bowel syndrome episodes prevent you from doing anything. Sometimes all three attack at once, when you might have been fairly okay an hour ago. Even if you try to get a good sleep, that doesn't mean you can have any energy on waking, and just because you baby yourself and take it easy before doing a planned activity doesn't mean you won't hurt. Coping is minute to minute every single day.

One consequence of pacing things out was that participants felt frustrated and dissatisfied in having to take so long to accomplish tasks and not seeing a project through from its beginning to its completion. One participant said:

Pacing my activities makes it difficult to get any sense of satisfaction. I seldom have the energy available to apply to an ongoing cause or a large project, and small projects do not satisfy my need for absorption and fulfillment. If I want to avoid setting off a pain cycle, it is best to break large tasks into small segments. Even with purely physical tasks, it can take so long to finish something; it is hard not to get discouraged. As one example, imagine that you are able to wash only one section of your kitchen floor per day, you will never have a completely clean kitchen floor, will you?

This same participant described how her self-esteem was threatened, because she could not complete things as a whole:

Sometimes pacing just doesn't work. When a bout of pain goes on and on, I have to use the strategy I most dislike. As soon as I begin to hurt, I stop. I just stop... I do as much of an activity and as soon as I begin to hurt, I stop. I do a bit more and stop again. Bit. Stop. Bit. Stop. Again and again, until I get a little physical relief along with a lot of cumulative mental aggravation. This technique eventually works but it is complicated. Not only do I have to figure out how much activity I can handle, totally losing my self-esteem and sinking into depression.
Another complication mentioned by the participants was that on some days they found that they had no choice but to put their pain and fatigue aside and do the things that had to be done, then endure the flare-ups of increased pain and exhaustion later. One participant who has to attend to her aging parents recounted:

No day is the same. No week is the same. Whatever, it’s ever going to become that way, so I can predict more, I don’t know. How do I cope? It depends what’s happening that day. Many, many times I can’t even think about how I’m feeling, I just have to go and do what I need to do, and then I pay for it later.

For some participants, especially those with young children, there was the constant striving to do normal things with their families, things that could set up repercussions of increased pain, fatigue, or a flare-up of symptoms after over-exertion:

Sometimes you do things like a normal person would and you know you’re going to regret it but you have to have some quality of life. You have to function. I have a child who is now 18 but when he was younger and I was first ill, you know I still had to try to find a way to do things with him.

In summary, the participants’ descriptions of their experiences showed that they were engaged in a constant balancing act as they made trial-and-error decisions on an ongoing basis: whether or not to use medications, exercise, comfort measures or other alternative therapies, and also whether or not to modify their daily activities and routines to help manage their symptoms in order to achieve a functional life without triggering “crashing” or “flares” of intense pain, fatigue or other symptoms, or suffering unduly from the side effects of medications. As the narratives indicated, maintaining this delicate balance between trying to simultaneously keep symptoms in abeyance while trying to live a life with some quality was, indeed, to walk a fine line. The participants recounted that while pain, fatigue and other symptoms served as cues to help them in this process of
maintaining a balance, at times they had to ignore their symptoms and do what they
needed to do in order to fulfill family obligations and to live a reasonably functional life.

Utilizing Support Networks

Participants stated that it was important to have a support network to help them
deal with the challenges of their condition. Most of the participants in this study got their
support mainly through their primary physicians with whom they developed relationships
and worked closely in order to develop an effective symptom management program.
They relied as well on a small circle of family and friends, and a limited use of programs
and support groups.

Maintaining Good Relationships with Health Care Providers

Participants had to utilize conventional therapies, exercise, alternative therapies,
various comfort measures, and modify their activities and routines in order to manage
their condition. To do this, they recognized that they had to work closely with various
health care providers ranging from physicians, physiotherapists, massage therapists, to
chiropractors, acupuncturists, and many other professionals. Physicians were most
commonly mentioned in these narratives because participants needed their help and
advice in experimenting with new medications or treatment modalities to deal with their
symptoms. As revealed in some of the narratives noted above, regarding the invisible
nature of FM, the relationships of the participants with their health care providers was
complicated by the lack of objective diagnostic data legitimizing the condition.
Participants stressed that it was important to develop and maintain good relationships
with health care providers who understood the experience of fibromyalgia, for some were
skeptical and unsympathetic. One participant shared her devastating and disturbing encounter with her rheumatologist, when, as she reported, he told her:

You’re obviously in pain, but there’s no reason for it. You don’t have arthritis. You know what hockey players do? They can break an ankle during a game, but do they let it get in their way? No. They keep on, and finish their game. They don’t even notice the pain. That’s what you have to do. You have too much time on your hands, and you’ve been babying yourself. If you continue to lead the inactive lifestyle you are leading, you can’t expect any result but pain. Get out there and do things. Get some exercise.

According to this participant, this was “not an isolated experience” for her; she had experienced it among many “practitioners who are not very sympathetic toward my chronic condition.”

Participants reported that it was unhelpful when some physicians were not able to offer them other possible solutions to their symptoms besides medications and disability. Some physicians were frustrated when their medical treatment was ineffective. One participant said:

There are few treatment recommendations. The primary options I have been offered by my doctor are painkillers, sleep medications and antidepressants. Once we had worked our way through those—nothing. Doctors are like other people: they like to succeed, and they find it discouraging to work with someone who does not get better. I don’t really know where to go; the only thing I’ve been offered one time, ah, before my current family doctor, I went to talk about it to a doctor and he was willing to put me on disability. He’s like, “Oh, do you want me to sign disability forms?” and I said “No, I am just trying to find a solution. That’s not what I want to do.” You know I just don’t see…the only options that have been presented to me to take the mixture of an antidepressant and a pain med, and to go on disability, and I don’t want to do either of those, so I guess I’m just hoping for some magical sort of things that somebody can just stop it from happening.

Participants stressed that it was important that their physicians be informed practitioners and recognize the limited effectiveness of conventional medications. It was also helpful if they were willing to learn and consider alternative strategies and to support and work
closely with participants in their efforts to try different methods to cope with their symptoms:

Finding a good doctor is imperative! Because I've had some unsympathetic or uneducated doctors, and to have one that trusts what's going on in your body, to give you a little credit for some intelligence. My doctor's willing, if it's safe and it's acceptable, to let me try different therapies. You need somebody who will listen to you and give you that credit for knowing what's going on in your own body and not just taking an imperative doctor role of, "I do know what's best or what I think is best for you, never mind what you think."

Another participant further elaborated the importance of a close working relationship with his physician:

Fibromyalgia is not an illness where you can walk into a doctor's office and expect that, after you've explained to him what you're dealing with, he will have a ready-made prescription for you and be able to give you a treatment regimen and say, "Here, this is what's going to fix it all up for you." It's very much... it needs to be very much a team experience. He needs to learn as much, if not more, from you as he can share with you. Hopefully he knows a lot about the condition and has, hopefully, a lot of patients that he's treated... The condition is self-managing in the sense that he [the physician] doesn't hesitate to increase the dosage if I request it. Or if I say, "I don't feel that this is working," so the patient has to be willing to be articulate and tell the doctor where... just exactly how you're feeling. The doctor also cannot come across as if it's more to do with the head, or he has all the answers, or there is a "cure-all" remedy out there.

Informants in this study made it clear that those with FM need to develop and maintain good relationships with their physicians as an important part of their illness experience, not only for the successful self-management of their condition in order to live reasonably functional lives, but also for their emotional well being. But, since FM has not fully accepted as a credible diagnosis by some physicians, there were instances in which some patterns of unhelpful communication occurred between physicians and patients. The narratives showed that this study's participants valued good relationships with health care professionals who offered sufferers of FM both empathy and recognition of their
experiences and symptoms, while supporting them as they managed to live with their condition.

Programs and Support Groups

All participants stated that although they were obtaining support from their significant others, families and friends, they tried not to burden them with their daily complaints of aches and pain, for they were aware that other people had their own share of difficulties, and that most people could not understand the details of their struggles. One participant said:

I don’t say very much because people don’t really understand; I talked to my doctor in detail but the rest of the time it’s just too much for people to take on. They don’t understand so I don’t say much about it. And it has been mentioned to me many times, “you... you look really well,” and I’ve had that comment on more than one occasion. But even if you are not feeling that well they still seem to think you look good, but they have no idea what you’re coping with inside.

Participating in an educational program for fibromyalgia was another way of getting help to deal with the condition. Though most of the participants in this study were aware of the existence of BCFS and its programs for people with FM, they managed their condition mainly with the help of their primary physicians. Others, however, joined educational programs or attended meetings organized by the Fibromyalgia Society, or involved themselves with support groups through the FM Society or the Internet. Three participants, when they were first diagnosed, joined an eight-week educational program offered at a local hospital for sufferers of FM and their families. They found the program very helpful. One participant said, “…the program was very constructive. It was exercise, we had doctors, we had pharmacists, physiotherapists, if I could have continued the program.” However, after completion of the program, there were only a few follow-up meetings, unfortunately held at other locations that were not readily accessible.
Some participants mentioned that there were not enough programs for people with FM due, they felt, to budgetary constraints. One participant said, “I can see there aren’t enough programs to help people, and the Canada Pension Plan really does not pay very much.” Moreover, some participants mentioned that services were quite disconnected; they had to drive to see their pain specialist, drive again to the chiropractor, or commute yet again to self-help programs. These participants believed that it would be helpful to have something more accessible in their communities. One participant went on to say that it would be helpful if there were coordination of all these services as a team, and that a one-stop service would be especially helpful:

I vision [sic] for any health condition where you have a team. Like in the hospital you do have a team working and so where chronic conditions where you’re living in your house, there was one place where you could go, where you could meet with a psychologist or meet with a social worker or meet with a nurse to help you deal with your medications, or even a physician who would come in, it would be ideal. And having a pool there for aquacise, having a physiotherapist who was specific about what needed to be done and then okay, say it was in Vancouver, well all the people in the outlying areas would have a hard time getting to it but if you, say, went through a treatment program of some sort...this is your treatment and for six weeks and then you go back into your community and you find those same resources, and yet the government pays for it. I mean if something...a model could be built where all these disciplines came together, and then when you go back into your community you could function with it. If everything was communicated like it is in a hospital where the nurse communicates something to the doctor, to the social worker, to the physiotherapist, to the occupational therapist...things are communicated and...but with this we’re out on our own and things...the patient has to take on so much of the burden.

Joining a support group was another option brought up by the participants. Several participants stated that it was sometimes helpful to connect with other people with FM who understood the unique struggles they were going through. One participant found a helpful counselor with whom she could share her experiences, and another participant said:
I have one very dear friend, she’s pregnant with FM and just between her and I, sometimes we don’t even want to talk about it. We just know that we’re not doing well and we understand but it’s good to have a good close friend that’s suffering like you are.

Most of the participants did not want to join a support group, and they gave a variety of reasons for this. They were unable to commit to regular meetings due to the unpredictable nature of their symptoms. Usually they found themselves too tired or in pain and it took too much energy and effort for them to access such group resources. One participant said:

I did belong to the Fibromyalgia Society but it was way across town. There was nothing that was local, and by the time you’ve driven there and parked and done all that, you’re a mess. And you come home in the same way.... I wished there was something set up. I think in our community because everybody lives near a community centre. And it would be an ideal thing to put up a program for fibromyalgia because you have to do different exercises at a different pace. And be able to share their experiences.

Some participants said it was disconcerting to join the Fibromyalgia Society since, due to the debilitating nature of FM, it was hard for the people who volunteered at this society, or similar groups, to get things done in an organized way. One participant said:

When I first got diagnosed and I contacted the society and went to a meeting over by Vancouver General Hospital there, they were somewhat disorganized, that is not surprising considering they suffer from fibromyalgia, and they were having problems getting the society going and stuff and keeping things happening and I did not keep up with them.

Most participants also found being around groups of other people with the same condition to be a depressing experience. They found that many in the groups were constantly complaining about how debilitated they were with their condition and about their frustrations with the government cutbacks. Such a litany of complaints negatively affected the participants and caused them to feel worse emotionally and psychologically. One participant commented:
I should have mentioned the fact that being in a group was rather depressing because you found that there would be whiners who couldn’t put up with any pain and didn’t put themselves forth to do anything, and just complained and complained. And yet there would be others that had far more pain that would smile. And their attitude was good, and so I just felt though that it wasn’t a good idea for me anyway to be in a group. It pulled me down.

Another participant recounted a similarly negative response to an experience with an Internet support group:

I looked for a group to join in this city because I wanted to learn more about fibromyalgia... I wanted to learn as much as I could as quickly as I could. I never pursued it, in part because on the Internet... there are a number of fibromyalgia sites that you can go to... support groups... perhaps more for the purpose of sharing with others and being a support, but therein lies a problem. I’m not involved in discussion rooms on the Internet any longer and the main reason is most often when people are coming on, all they are doing is they are whining and complaining and groaning and on and on and on. I don’t want to sound cold about it but I think there has to be a balance. You can...fibromyalgia can start to control the person where it doesn’t look like there’s light at the end of the tunnel. I believe there is. I may not reach a point where I’m going to be like I was, but I think things can improve and hopefully will improve.

Two participants stated that it would be helpful if the groups, instead of “complaining”, learned to engage in doing something productive together, such as lobbying the government to facilitate the disability application process and the approval of more treatment modalities under health care coverage so that people with fibromyalgia could afford all the different treatment avenues available to help manage their symptoms. One participant said:

I think a lot more can be done in recognizing the severity of fibromyalgia. I know that in Holland, for instance, they have a national organization that works very hard to help people through the process of applying for different disabilities. I know this is not so in Canada. They do have a society for fibromyalgia but I don’t think they are lobbying on their behalf, as they ought to be. I think we need a political body behind this disease or this condition so that we can actively work as a group to make a difference... to be productive together.

This participant also suggested some other fruitful activities a group can do together:
I think some kind of support groups could be formed in a sense that rather than a
group that talks about their illness, is a group that contacts itself to [know] how
can we best stay healthy. Maybe an exercise class for fibromyalgia people
specifically. Or a group that will explore artistic abilities, how can we be creative
while we have this problem? I mean finding ways to be joyful so I could see
poetry going on or expressions of art form, having a forum on fibromyalgia.
Specifically a forum for friends and family or even church or any other group that
would like to know more about it so people can recognize that while you can’t see
it, we do struggle a lot. ...I think we should be able to form a political body that
can go to the government and say, “We’re all fibromyalgia patients. Now massage
therapy was really working for us, why have you taken it away?” So we can be an
active lobby group...to be productive together. Not to be negative together.

One participant mentioned that it might be helpful for a health care professional to help
facilitate a group. This participant said, “I think support groups shouldn’t be just whining
and complaining, but actually have somebody leading it or dealing with it in some
manner, I have heard of a doctor that does a twelve step program for fibromyalgia.”

Informants in this study, in their comments about the support available for people
with FM, pointed out that not all the resources available to them were necessarily good
for them, or helpful. While participants sometimes valued existing support groups for
people with fibromyalgia, all participants also sometimes found the groups disappointing
or difficult to attend and not adequate to meet their need for emotional and social support.
The participants gave several suggestions regarding what they wanted from support
groups, suggestions that might assist health care providers in helping patients with FM set
up groups specifically tailored to their needs.

*Striving to be Productive*

Another means that participants used to cope with their living with fibromyalgia
was an ongoing attempt to be productive in spite of their inability to contribute to the
workforce. Many of the participants in this study were involved in volunteer work. They
helped in church activities, volunteered in ESL courses or other community services, did
craft work, or spent time encouraging others who were in similar situations or facing other difficulties in their lives. The participants felt that it was important to be useful and productive in order to maintain their sense of self-worth. As one participant explained:

"You have to stay productive. I think we have to remain part of the world because we tend to isolate from the world because again it's an invisible illness. And I think it is good to keep yourself involved in something. For your self-worth. Something you're interested in. Maybe you're interested in art, maybe you could be down at the museum or the arts studio in some way to volunteer."

Another participant stayed productive in a different way:

"I can't work you know but I do sew. I can't sew for hours but I can sew and I can make small quilts. I've learned to limit myself. If I can't make a big quilt, I can make a small quilt. I can't make 20 cards, but I can make 3 cards... I think it's critical that you stay productive. Because it gives you a sense of well-being... because if you are not productive, "well, you say, what is the use of living?" So find ways that other people can appreciate what you do. Maybe not having a full time job or not having a job at all, that's okay as you can be productive in many different ways. The other nice thing about being a volunteer is that it is flexible; unlike a steady work schedule where they have to be at work at a set time and set place that is a challenge for these people.

One participant, in contrast to the others, did not feel that her life was productive because she equated her sense of achievement and definition of self to her job status. She did volunteer work and housework, undervalued these, noting that her inability to contribute to the paid workforce had affected her feelings of self worth and self esteem.

This participant said:

"Most of my energy is used up by the activities of daily living, self-care, housework, grocery shopping, meal production, laundry, chores etc., activities that are necessary but leave me with no sense of accomplishment. In the larger world, no one is impressed by how well I take care of myself, my husband, my household and my daughter, no matter how well I do it. Neither are people impressed by the volunteer work I do. Those are not activities that gain me any recognition or status. I miss status, something that is obvious."

This same participant further explained:
I look after myself and my daughter the best I can. I do volunteer work for the housing co-op where I live. I volunteered at an adult Learning Centre. After fourteen years of living with a chronic illness, I have few friends left, but I respond as best I can when those friends need me. My mother is eighty-three years old; my sister is sixty-two and severely disabled: I help them when I can. I keep a daily journal in that I record all my activities so I can look back and see that, despite how I may feel, I have not been inactive, but I can't honestly say that any of that makes me feel productive; it just keeps me human.

Despite the desire of people with FM to perform some volunteer work, some felt the set-up of the disability system worked against them. According to one participant, if people with FM were not able to do paid work and were on disability, and yet were able to do volunteer work, this could be wrongly perceived by others, and lead them to further doubt the incapacity of people with FM to remain in the paid workforce. This participant explained:

But how much volunteering does a person do? Well, maybe they try to do as much as they can. How is it going to be perceived? What's going on here? That's...that's a Catch 22 in a way. This thing of being totally disabled can be very nebulous. It can be very nebulous and I can understand people who have fibromyalgia becoming somewhat paranoid or they can be convinced because they feel “Well, I know I can’t work; certainly not in the capacity that I was at and there’s nothing out there that I can get involved in and actually sustain anything.” It’s really...people have to be realistic and realize you can’t just decide that well, if a person mows their lawn or if she plants flowers for an evening, that they’re not disabled any longer. Like one fellow I read about was gardening and he was viewed...he was seen by a member and it was reported and he was taken off disability and the physician...his primary physician had to tell [the authorities] that gardening is at least some form of exercise. Well, that’s common sense tells a person that and yet, the “powers that be” [inaudible] so what’s the agenda? It’s very difficult and then of course it’s how is it being “read” by those who are in the position to make decision about whether you are still eligible or not. So I can understand people with fibromyalgia being concerned about that.

As these accounts suggest, it is important to consider the experiences of living with FM, therefore, needed to be considered in the context of the individuals’ own definitions of their goals and values in life. Though it was helpful for people living with FM to stay active for their well-being, they were also aware that their actions might be
perceived differently, or misperceived, by others who believed that any activity at all meant the sufferer of FM was in fact capable of paid work.

**Summary of Findings**

Thematic analysis of the data from interviews with participants revealed a number of interconnected commonalities in the participants' accounts of living with fibromyalgia within the overall context of their lives.

The first theme concerns the complexities of living a life with FM, which participants note entailed experiencing a wide range of complex symptoms that were constant, varying, unpredictable and invisible. Pain, sleep disturbance, fatigue, mental cloudiness, and irritable bowel syndrome were some of the common symptoms mentioned. Frequently, informants noted that their symptoms worked in a vicious circle that affected their lives and presented significant challenges to the management of the condition. It was clearly revealed in the participants' narratives that the complexity of these symptoms and their interrelated effects impinged on the participants' physical, emotional, and psychological well-being. The impact of FM did not stop there, however, for the condition also affected participants' relationships with family and friends, and severely influenced their careers and economic status.

A second theme, the management of FM, included two main sub-themes. The first was trying to find and maintain a balance, using a combination of approaches: the use of conventional medicines and therapies, the use of comfort measures and alternative therapies, and the careful modification of their daily activities and routines. The second sub-theme was utilizing support networks, which participants accomplished through
maintaining close relationships with health care providers, and using discretion in choosing support groups.

Finally, a third theme revolved around the nature and influence of the wider context that encompasses the social, health care and political context of living with FM in British Columbia today. This theme was embedded in the preceding two themes concerning living with the symptoms of FM and its management, but will be discussed separately in the following chapter because of the overarching implications for the entire illness experience.
CHAPTER FIVE: DISCUSSION AND IMPLICATIONS OF FINDINGS

There are a number of common elements between, and linkages with, the findings of this study and the current body of literature on FM. The purpose of this chapter is to discuss the findings and their interpretations, both in relation to this literature and, more broadly, to the literature on chronic illness. The findings of this study indicate that key aspects of individuals’ experiences of living with FM follow several interrelated, major themes. The first of these themes is living with the symptoms of FM. The second theme is the management of FM, and the third theme focuses on how the social, health care and political contexts shape the experience of individuals living with FM. These three themes are not mutually exclusive but, in this chapter, they will be discussed separately in relation to the specific literature on FM and, more broadly, the literature on chronic illness. The discussions of these themes reveal areas in which the findings of this study may add to the knowledge of FM, raise issues for further investigation, or may have implications for practice.

Living with the Symptoms of FM

FM encompasses living with a wide range of symptoms that are constant, varying, unpredictable, and invisible in nature, which adds to the complexity of living with the condition. In keeping with the findings of other studies (Creamer, 1999; Inanici & Yunus, 2002; Johnson et al., 1990; Vanderhaeghe, 2000) diffused, generalized musculoskeletal aches and pain, fatigue, short-term memory problems, irritable bowel syndrome, and disruptive non-restorative sleep are some of the symptoms of FM reported by the participants in this study. A number of studies on FM (Hallberg & Carlsson, 2000; Henriksson, 1995a, b; Mannerkorpi et al., 1999; Soderberg & Lundman, 2001; Soderberg
et al., 1999; Sturge-Jacobs, 2002), note that the complex constant, varying, unpredictable, and invisible nature of the symptoms has an impact on the physical, emotional, psychological, familial, social, and economic aspects of the affected individuals' lives. Participants in this study confirmed that these impacts are profound, life-changing, and for some, all-consuming.

Dewar and Morse (1995) theorized that some factors of an illness experience may render living with the illness unbearable or unmanageable. These researchers describe such factors as assaults; these may be interpersonal, that is, due to the reactions of others, or they may be intrapersonal, that is, associated with the symptoms or treatments of the condition. Participants in this study found this to be the case, noting certain factors that make their experience of living with FM unbearable and stressful. In the context of their daily existence, the presence of unrelenting symptoms that are not consistently amenable to treatment modalities pervades the lives of those with FM. The lack of objective diagnostic data to establish the credibility of their existence also creates additional stress and presents further challenges to people living with the condition. In the broader health care and social contexts, people with FM had to deal with the tendency of others—including some health care professionals, friends, family members, and colleagues—to discredit their illness. Participants were unable to change these aspects of their situation, and so they learned to endure them to the best of their abilities. Some research suggests that sufferers of some chronic conditions and some people with FM (Asbring, 2001; Schaefer 1995a), are able to live with their symptoms by relegating them to the background of their lives. However, participants in this study, congruent with the findings of other research (Hallberg & Carlsson, 2000; Hughes, 2000; Soderberg et al.,
1999; Sturge-Jacobs, 2002), reveal that for them, this seems not to be the case. My study shows that people with FM continually place a major focus on getting their symptoms legitimized and alleviating the suffering associated with them. Paterson (2001b), in her shifting perspective model, theorized that adults living with chronic illness tend to shift the focus of their attention from wellness to illness in the foreground of their lives when illness-related threats exceed their threshold of tolerance in living with the condition. Participants in this study noted such a shift, citing the cumulative effects of illness-related losses. These include the interrelationships surrounding the complex nature of the symptoms and their impacts, the distress related to the lack of legitimacy accorded their symptoms, the continuing effort to alleviate their symptoms, and the unpredictable response of their symptoms to treatment modalities. All of these presented ongoing threats to this study's participants’ ability to relegate their symptoms and condition to the background.

Paulson et al. (2002), Soderberg et al. (1999) and Sturge-Jacobs (2002), note that such illness-associated threats have brought about emotional turmoil and distress for people with FM. However, some studies of FM (Asbring, 2001; Henriksson, 1995a, b; Hughes, 1999; Soderberg & Lundman, 2001; Soderberg et al., 1999), suggest that people with FM do integrate their new identities into their lives and develop new capabilities to deal with the condition. A few researchers even report that some persons with FM perceive some changes resulting from their condition as “illness gains” (Asbring 2001; Howell, 1994) that bring about increased self-respect, personal integrity, and positive growth. On the contrary, participants in this study did not view the consequences of
living with their FM as illness gains. Instead, they saw the effects of the symptoms as limitations on their lives that they needed to allow for and work to circumvent.

In spite of these challenges, as Hughes (1999) and Schaefer (1995b) note, those with FM are not without hope. Indeed, the participants in this study revealed that they tried to nurture hope and maintain a positive attitude in order not to succumb to the limitations brought about by the condition. They hope thereby to maintain some normalcy in their lives.

**Implications**

From the foregoing discussion, it is evident that this study and others indicate that living with FM involves experiencing a complex range of symptoms that affect many areas of the individuals’ lives. As a result, these individuals do experience emotional challenges. A few studies (Asbring, 2001; Hughes, 1999) report that people with FM sometimes view their condition positively. However, participants in this study stated that they do not perceive their illness as having positive effects, although they do try to nurture hope. Furthermore, while they recognize the reality of the condition, none of them totally accepts the limitations of the condition. This seems to echo Paterson’s (2001b) claim that nurses need to understand “statements of optimism and pessimism, not as failing to understand the reality of the disease, but as indicators of the person’s perspective” (p.25). Both Paterson’s claim and the findings of this study, then, refute the belief among some health care professionals that they need to assist chronic illness sufferers, on the one hand, to accept their losses, and on the other hand, to view their losses as an opportunity for personal growth. Such a perspective is not one that participants in this study were inclined to appreciate or accept.
Paterson (2001b) also argues that health care providers need to support patients based on each individual's perception of his or her own experience of living with the chronic condition. Participants in this study clearly articulated a perception that they needed such support. The findings in this study, in keeping with other studies (Asbring & Narvanen 2002, 2003; Bernard et al., 2000b; Henderson 2002; Schaefer 1995a, b) suggest that health care professionals ought to recognize the pressing need that people with FM articulate for support in their efforts to live with their condition and its impact. They suggested, for example, that it would be useful for health care providers to help people with FM to assess their vague varying symptoms and to provide better support for them in their many illness-related stresses.

Management of FM

There is no known cure for FM (Ledingham et al., 1993; Russell, 1998), and treatment entails mainly the management of its symptoms (Clauw 1995; Sylvain and Talbot 2002; Wassen et al., 2002). The findings of this study agree in the main with those of other researchers (Hughes, 2000; Inanici & Yunus, 2002; Soderberg et al., 1999; Sturge-Jacobs, 2002) that people with FM tend to focus primarily on the management of their symptoms since their unrelenting, unpredictable nature present numerous and continuing challenges in their living with the condition. Not only is FM at present incurable, conventional medicines alone do not adequately relieve its symptoms. Moreover, these symptoms may respond unpredictably to various treatment strategies at different times. As Adams and Sim (1998), Estrada and Cook (2000), and Jones (2001) note, those who live with the condition may resort to alternative therapies. This is the case with participants in this study, who revealed that among the strategies they employ
in symptoms management are various alternatives to conventional, biomedical therapy since biomedical options fail to adequately provide the support that patients with FM need.

**Trying to Find and Maintain a Balance**

My study seems to reflect the categorizations depicted in Mannerkorpi et al.'s (1999) study on the management of FM. In that study, participants perceived their symptoms and management of the condition in one of four discrete themes: struggling (having the strength to fight their symptoms); adapting (being able to manage and cope with their limitations); despairing (not being able to cope with their symptoms); or giving up (allowing the symptoms to control their lives). The participants in this study related that although these perspectives do apply to their management of the condition, they did not see these as discrete and mutually exclusive themes. Instead, they experienced struggling, adapting, giving up, or despairing at different times and on different days, depending on the variability and severity of their symptoms or on other additional stressful events.

The participants in this study repeatedly used the metaphor of trying to find and maintain a balance to discuss their continuing search for various solutions to relieve the never-ending suffering associated with their symptoms. In some studies, notably that of Paterson, Thorne and Dewis (1998), a meta-analysis of 43 qualitative studies, the metaphor of balance has been used to refer to the strategies used for self-care management in order to live a normal life with diabetes. Paterson and her colleagues found that learning to manage diabetes is a lifetime ongoing process of “knowing the body and adapting the routine each time individuals encounter unexpected body
responses to interventions or situations” (p.60). While people living with diabetes tend to focus on wellness instead of illness (Hamera, 1992), people living with FM tend to focus on their illness. This suggests that persons with FM may perceive the concept of balance differently than persons with diabetes.

The metaphor “struggling to maintain a balance” was also a theme used by participants in Schaefer’s (1995a) study of people with FM to refer to each of the following areas: reflecting on their lives before the diagnosis, working through the diagnostic process, attempting to manage symptoms, and moving on to live with a new reality. According to Schaefer, struggling to maintain balance continued as participants made choices about their lifestyle and activities, modifying the way they did things and making choices between medical or alternative strategies in order to manage their symptoms.

Although this study’s participants raised issues similar to those reported by the Schaefer (1995a) study, they stressed that to learn the art of finding and maintaining balance was a complicated process. Participants learned about this process over time as they grappled with the decisions about their activity levels, and tried various lifestyle modifications and coping strategies. Moreover, because their bodies did not always respond to given strategies in the same way each time, they also needed to consider a number of treatment options. To manage their condition, then, patients with FM had to decide continually when to modify lifestyle, activities, and rest, and whether to use medications for symptom relief while enduring their side effects or to endure the pain of FM to avoid undesirable side effects of the medications. Sometimes, the participants would give up and let their pain and symptoms dictate their activities for the day, and
resume the struggle to maintain balance another day. This pattern in FM seems related to
a similar process noted by Shaul (1995), who studied problems faced by those patients
suffering from RA: they “learn to live with the condition [until they achieve] mastery in
living with it” (p.201). Although we understand FM and RA to be distinct diseases, many
symptoms are common to both conditions. It is possible, therefore, that some findings of
RA studies may help to shed some light on the FM experience. For example, Shaul’s
notion of mastery of RA symptoms applies equally well in FM; that is, both seem to
entail goal-directed, ongoing processes of decision-making that extend beyond discrete
coping strategies. In this study, no clear pattern was evident in the way participants
decided among various strategies; typically, they tested these by trial and error to avoid
strategies that would worsen their symptoms. For example, individuals in this study
tended to make decisions about activities they could engage in without causing a physical
“crash.” They perceived that this process was part of their ongoing attempts to find and
maintain balance. For this study’s participants, then, this decision-making process tends
toward the goal of finding and maintaining balance—as opposed to achieving “mastery”:
this, I suggest, may be an important distinction.

Implications

This study’s findings clearly support the notion that management of FM is a
complex process involving a combination of various strategies that those with FM
employ in their attempts to find and maintain a delicate balance. Thorne et al. (in press),
in a recent study, suggest that patients with FM believe that health care professionals
need to be willing to work with them as they go through a process of trial and error to
discover how each individual patient may best manage his or her illness. Additionally,
Bernard et al. (2000b), Clauw (1995), and Gremillon (1998) recommend that health care providers need to ensure that people with FM are making safe decisions in their choice of conventional and alternative therapy as they employ various strategies for symptom management. Although multiple approaches to symptom management are used by people with FM (Inanici & Yunus, 2002; Jones, 2001), the findings of this study point to how little is yet known about how these individuals select each strategy. To help each patient achieve and maintain that fine balance in symptom management, participants believe that caregivers need to be aware of the complex, idiosyncratic, and individual nature of this process. Further research exploring decision-making processes used by people with FM will likely shed useful light on this process and provide new insights for professionals seeking to offer better care to and support for their patients.

**Utilizing Support Networks**

Participants in this study noted that, in addition to seeking balance, it is important that they establish support networks as another way to manage their condition. For instance, they reported that they obtained some support through their primary physicians, and from other health care professionals with whom they had worked closely to develop an effective symptom management program. To supplement the support of health care providers, most of the participants in this study spoke about obtaining additional support through formal face-to-face and Internet support groups, or through a small circle of family and friends.

**Maintaining Good Relationships with Health Care Providers**

The literature on FM contains numerous references regarding the importance of good relationships with health care providers for people to effectively live with and
manage their FM (Bernard et al., 2000b; Poro-Boisset et al., 1996). When discussing their own experience in such relationships, for the most part this study’s participants referred to their physicians. This was because participants were usually in close contact with the physician to secure a diagnosis, obtain knowledge about FM, monitor symptoms, and seek support in the long-term management of their FM. However, participants also referred to nurses and other health care providers.

As Toombs (1993) notes, the training of physicians predisposes them to give precedence to observable, objective data as valid knowledge; this training shapes the context of health care delivery. As other researchers studying FM have reported, many people with FM have observed that there are physicians who favor the curative model of medicine and prefer to treat people with a disease or condition that has distinct clinical signs and symptoms (Hellstrom et al., 1999; Sylvain & Talbot, 2002).

Some studies such as Hadler (1996a) and Webster (2000) note that, because of the lack of discrete, objective data to support the diagnosis of FM, some physicians refuse to recognize FM as a valid medical condition. These authors suggest that some health care professionals therefore perceive that people with FM are care-seeking or malingering, and that the suffering of these people is “all in their heads.” Such assumptions create tension in the patient-physician relationship, as some FM studies note (Aaron et al., 1996; Carey et al., 1995; Jones, 2001, Maurzio & Rogers, 1997). As I noted in the previous chapter, participants in this study revealed that not only did such an attitude to the symptoms of FM create tension in the relationship when they encountered it, but also that the resulting tension contributed to the patient’s distress. This constituted an additional, unwelcome burden. Participants in this study observed, in accord with the findings of
Thorne et al. (in press), that when people with FM are unable to rely on their physicians for emotional support and empathy, this greatly increased their already acute feelings of devastation and suffering.

An additional problem, noted by other studies on FM (Asbring & Narvanen, 2002; Hellstrom et al., 1999; Sturge-Jacobs, 2002; Sylvain & Talbot, 2002; Thorne et al., in press) is that persons with FM find it unhelpful when they perceive that their physicians approach FM from an exclusively biomedical perspective. According to this study’s participants, biomedicine typically provides only temporary and partial relief of some of the symptoms of FM. As Royer (1998) observes in a study of chronic illness, the biomedical model tends to confine patients to being “biological organisms with disease as an external threat to be cured... [something that] may be appropriate within the context of acute illness, but is not useful for the management of chronic illness” (p.168), an observation echoed by the Dunkin (1997) study on people with FM, as well as the participants of this study who observed that the biomedical perspective—the view that every medical problem has an organic or biochemical cause—does not best serve the needs of people with FM whose symptoms have no known pathology and do not consistently respond to treatment strategies. In contrast, this study's participants reiterated the findings of other researchers (Asbring & Narvanen, 2002; Bennett 1996b; Bernard et al., 2000b; Hadler 1996a; Henderson, 2002) that people living with FM want their health care providers to validate the reality of their condition, to affirm their suffering and to look beyond the biomedical perspective which cannot provide the holistic interpretation that is required to meet the full needs of these people. From the perspective of this study's participants, a holistic perspective is an essential element of effective health care:
a holistic approach would offer physical, emotional, mental, and spiritual support, acknowledge the suffering that FM entails, and help to sustain individual efforts to live with and manage the condition.

The findings of this study, similar to the findings of Thorne et al.'s (in press), found that some health care professionals are ill-informed and unwilling to learn about FM, and offer medications as the only solutions for the condition. Since encounters with health care providers of the latter type are unhelpful, participants in this study reported that they value (or would value, if it were available) good, helpful information from those of their health care providers who are willing to work collaboratively with them to help reduce the debilitating effects of their symptoms. Thorne, Nyhlin and Paterson (2000) and Thorne and Paterson (1998) considered health care relationships in their studies of chronic illness. They found that when the relationship is based on the notion that the health care professional is the expert and the patient is the passive recipient of that expertise, the health care provider cannot adequately assist sufferers of chronic illnesses in the long-term management of their conditions. Participants in this study described situations in which some health care providers had denied the validity of FM, citing their biomedical expertise. Therefore Thorne et al.'s (in press) observation may well apply to people with FM. This study's participants often observed that they valued, or would value, such a willingness to collaborate with patients in managing FM. On the other hand, participants reported that, when they experienced negative interactions and perceived medical experts' behaviour as insensitive, they experienced a considerable level of stress in having to live with their condition.
Support Groups

The findings of my study seem to suggest that the type of support that most of this study’s participants prefer to receive from health care providers is not necessarily forthcoming. Participants in this study, therefore, sought support from organized groups as another key strategy in the process of managing their FM.

In the broader field of chronic illness, research shows that social support plays a key role in buffering stress and promoting health and emotional well-being. For example, Bloom (1990), Callaghan and Morrissey (1993), and Weinert (2000) have conducted studies that show social support has a positive influence on illness management, especially when chronically ill persons receive support from people with the same health problems (Helgeson & Cohen, 1996; Thorne, 1993). Oliver et al. (2001), who examined the role of support groups in helping people with FM, found those persons with FM who received social support handled their illness more effectively and seemed to have lower levels of distress and depression than those who did not.

Dewar (2001) found that maintaining social support and preserving interpersonal relationships are important resources used by people with chronic illnesses in managing their condition, and observed that: “Strategies such as limiting information, hiding symptoms, minimizing emotional responses, limiting requests for assistance and sharing problems with outsiders lessened the distress of their significant others and preserved these important relationships” (p.605). Participants in Dewar’s study were not living with illnesses such as FM, that is, illnesses which lack agreed-upon diagnostic criteria and social credibility. But her findings may be applicable to people with FM as participants in this study followed a similar strategy. They were equally careful not to overburden others
with their problems and, somewhat paradoxically, they avoided magnifying their own distress during social interactions, as they perceived it would be counterproductive or undesirable to cause too much upset for their friends, family and others. Consequently, participants used protective strategies such as trying not to talk excessively about the challenges they encounter living with FM to minimize such undesirable outcomes.

Although these issues may affect or limit the support network of people with FM, this study’s participants apparently perceived the potentially alienating effects of upsetting and burdening others with their complaints. This relates to individual relationships and also to interactions within support groups.

Participants in this study discussed a range of social supports including the Internet, friends, family, and formal and informal groups. Their perceptions of the benefits and costs of participation in support groups suggest a somewhat more complex picture than previous studies have noted. Specifically, participants did not always find that the benefits outweighed the costs when they sought such support strategies. Heller, Swindler and Dusenbury (as cited in Swanson & Tripp-Reimer, 1997) assert that social support “influences health and well-being not through its presence but in the way it is perceived. Consequently, it cannot be assessed apart from the meaning of relationships and activities to individuals” (p. 138). One of the most striking findings of this study relates directly to this assertion. In this study, participants reported that, although they valued the presence of support networks in helping them live with FM, they did not perceive some support as beneficial. Specifically, when people in the group chose to dwell on their struggles and suffering as they lived with the illness, group members felt this had a negative effect on their emotional and mental health, and also that of others.
That is, participants, as in this study, as in Dewar’s, felt they had to learn how to avoid the depressing impact upon their emotional health induced by the complaints of others suffering from the same condition with whom they interacted in a support group context. In other words, it was not the presence of support that counted, but how those seeking support perceived it. As this study’s participants pointed out, the negative as well as the positive aspects of their social interactions did clearly affect the perceptions of the people needing social support.

Similarly, Vickers (2001), in a study of unseen work in chronic illness, postulates that social support has both costs and benefits. In this study, participants did reveal some elements of both the helpful and unhelpful aspects of social support in their situations. On the one hand, participants found it helpful to join groups that met their emotional and informational needs, or that engaged in beneficial activities together to promote well-being. On the other hand, they found that joining a support group was not helpful when the group consisted of fellow patients who were constantly “whining about their condition” as they put it. People with FM usually led such groups; health care providers were seldom facilitators. In view of this problem, participants repeatedly stated that they would prefer health care providers, rather than people with FM, to facilitate support groups for people with FM. This finding warrants further investigation.

**Implications.**

As this study’s participants have pointed out, both good relationships with health care providers and support groups constitute important aspects of living with and managing FM. However, they note also that it is not always easy for people with FM to maintain good relationships with health care providers. These relationships may be
complicated both by the lack of discrete diagnostic tests for FM and the context in which health care is provided to people with FM, in which diagnosis tends to depend primarily on clinical findings. The findings of this study suggest that, when health care professionals focus mainly on the biomedical treatment of symptoms, they do not serve the needs of people with FM as well as these patients feel they need and deserve.

Previous studies (Bernard et al., 2000b; Dunkin, 1997; Sylvain & Talbot, 2002) have noted this implication for people with FM, and have pointed to the possibility of a more comprehensive approach to FM than the biomedical one. Ideally, health care providers would abandon the symptom management perspective, and avoid the tendency to compartmentalize FM with other chronic medical conditions. According to participants in both Dunkin and this study, more health care professionals need to approach and understand FM holistically, addressing the emotional, mental and spiritual aspects, and the social and cultural contexts of the illness. The findings in this study, in keeping with Alamo, Moral and de Torres (2002), Bernard et al. (2000b) and Thorne et al. (in press) suggest that people with FM want their health care providers to be better educated and informed about their condition, to validate its existence, to offer empathetic non-judgmental support, and to work collaboratively with them as they explore various alternatives for symptom management.

That there are helpful and unhelpful aspects of support networks for people living with FM is an issue participants in this study have discussed and other researchers (Bolwijn et al., 1994; Oliver et al., 2001) have investigated. It seems that some people with FM tend to limit their social support networks in order not to overburden friends and family. They also apparently make efforts to render their symptoms invisible, or at least
less visible, to others. Thorne et al. (in press) suggest that, in such situations, the support of health care professionals seems to be the only viable outlet for these people seeking sympathy and support. A finding of this study was that, despite the stated limitations of some relationships with health care providers, the nature of this complicated and misunderstood condition seems to leave this avenue of support as one of the patient with FM’s primary options for social support.

When the findings of this study are considered in the light of other work on social support in FM, or on other chronic illnesses, it is evident that there are many reported benefits from such support. Yet, Bolwijn et al. (1994) have suggested that further research is needed to better understand the role of social support for people with FM, a suggestion echoed in this study. In particular, this study’s findings seem to suggest that the question of whether or not health care provider-facilitated support groups will minimize the depressing aspects of formal support groups and increase the helpful ones should be investigated. In the interim, the emphasis this study’s participants placed on their need for health care provider-facilitated support groups suggests that patients should be encouraged to seek such groups, and that health professionals should be ready both to refer patients to them, and to provide them, if possible.

The Wider Context of Living with FM

The findings of this study seem to suggest that it is important to consider not only the immediate context of FM—diagnosis, symptom management, support, for instance—but also the broader health care context, as well as the societal and political contexts that affect how individuals live and manage their FM. In the previous section, I noted the extent to which the failure of members of the health care community to recognize and
legitimize the condition increases the suffering of the people living with FM. Vickers (2001) postulated that the medical profession may influence certain broader societal constructions beyond the specifically health care environment. For example, it is health care providers who may influence the determination of which illnesses are socially acceptable, thereby affecting the attitudes of the lay community toward people with certain chronic illness. Our society is socialized to have "complete faith in the value of scientific medical knowledge" (Calan & Williams, 1992, p. 233). The participants in this study have alluded to the social stigma that results from living with FM, and the FM literature contains numerous references to this aspect of the condition (Asbring & Narvanen, 2002, 2003; Sturge-Jacobs, 2002). Thorne (1993), in her study on invisibility and chronic illness, noted that society's "...abstract notion of what is normal becomes the standard against which much of life is measured by and for the chronically ill" (p. 75). It seems that society, at present, does not recognize FM as a "normal"—and therefore acceptable—chronic condition; not, in any case, in the same way as it accepts medical conditions such as diabetes or arthritis that have distinct pathological abnormalities.

Typically, society perceives illnesses as credible if they have visible, objective symptoms or limitations. Fatigue and pain, the two main symptoms of FM, are both subjective experiences. According to Thorne (1993), we usually view fatigue as a minor inconvenience and an effect of illness and thus it is difficult for others to comprehend the magnitude of non-relievable fatigue's effect on people with FM. Similarly, we all experience tiredness and we manage to carry out our daily life activities and get things done in spite of feeling weary. It is hard for those of us not suffering from the condition, therefore, to understand why people with FM, who have no visible signs or universally
accepted diagnosis of illness, are unable to do likewise. Tiredness, however, is not synonymous with fatigue: in the presence of the former, sleep is restorative; in the presence of the latter, no amount of rest provides relief. Likewise, pain is acceptable and will evoke sympathy if the sufferer experiences it, for example, in relation to injuries, childbirth or cancer. Sympathy is not as immediately forthcoming if there is no immediately apparent cause for the pain.

Drawing upon Thorne’s (1993) observations that the standard for what is normal seems to shift in the face of chronic illness, as well as upon the findings of this study, we can see that the “normal” (that is, apparently healthy) appearance of patients with FM hinders the ability of others to accurately perceive how ill the person with FM may actually be. As participants stated, others (including their families, friends and members of their social circles) are not always able to appreciate how pain and fatigue limit their ability to be able to engage in activities of daily living, because they looked “normal.” As shown in this, and other studies (Asbring & Narvanen, 2002; Sturge-Jacobs, 2002), this problem has resulted in cases of enacted stigma and has increased the stress of living with FM. Experiencing stigma has caused the affected individuals to be careful to protect themselves in the disclosure of their condition.

As noted earlier, such stigmatizing also occurred in participant interactions with some health care providers. Our general social context, which includes the health care profession, predisposes us to assume that a person whose appearance is normal must be healthy. Thus, our acculturated constructions of what constitutes “normal” (healthy) and “abnormal” (ill) may quite possibly be related to some health care professionals’ decisions to refuse to recognize the normal-looking person with FM as legitimately ill.
There are other ways in which social structures influence the lives of those with FM. As Paterson (2001b) states, "...social and health care structures and policies also reinforce an illness in the foreground perspective..." (p. 25). Participants of this study stressed that the debilitating effects of their symptoms hinder them from engaging in full time and regular employment. At the same time, the findings of this study reveal that the participants faced a conundrum: although they might want to work, they might be ill-advised to do so if, for example, they wanted to be considered eligible for disability benefits. The participants also noted that, when they were able to engage in some forms of work or physical activity, this caused some health professionals and the disability claim authorities to express doubts about the credibility of their diagnosis, particularly when the cause of such a need is both invisible and disputable. Consequently, seven participants in this study have had to leave their employment, go on disability benefits, and become reconciled to the fact that they must live with reduced economic resources and struggle to meet their daily and health care needs.

For participants in this study, the suffering of living with FM did not seem to lessen when they received a diagnosis. Hadler (1996a, b) reports, as did this study's participants, that people with FM also encounter difficulties and additional stress when they have to fight for their disability benefits. This occurs due to the absence of definitive laboratory or radiographic tests to diagnose FM. Our social security systems do not easily grant monetary benefits, and there is a need for claimants to prove themselves incapable of doing any work in order to be eligible to receive government disability benefits (Wells & Hammitt, 1998; Hadler, 1996a, b). These difficulties seem to be exacerbated in the FM situation, where there is a "notable blurring of definitions among conditions of chronic
illness, disability and long-term care as not all chronically ill individuals are functionally disabled” (Royer, 1998, p. 169). Consequently, physicians have to take the needed procedural step of ordering a full regimen of medical tests before granting benefits, for not only can the symptoms of FM arise from other causes, it is also known that a motivated and skilled deceiver could simulate the symptoms of FM (Khostanteen et al., 2000; Wolfe, 2001). Therefore, medico-legal and compensation decisions must be based on some objective findings. It is therefore difficult to rationalize the decision to grant disability benefits to those who have “tender points” with reduced pain thresholds but no supporting pathology (Bennett, 1996b; Wolfe 2001). Moreover, the ready granting of disability benefits for patients for FM would have economic implications for society as a whole (Bruusgaard, Evensen & Bjerkedal, 1993). Therefore, participants in this study, like those in Hadler (1996a), have had to surmount a long bureaucratic process of undergoing various medical tests by their physicians and other specialists in order to validate their condition and to get their disability papers signed. This has greatly increased their stress of living with their condition. Such difficulties in diagnosis, due to the absence of definable impairment, have prevented people from receiving immediate help. Instead, the process subjects people with FM to being “drawn into the vortex of disability determination...” as the agencies’ “interest is vested in questioning the veracity of the claimant’s symptoms,” (Hadler, 1996a, p.2398-9). All such factors have significantly affected the individuals’ experience of living with FM. The findings of the study seem to suggest that, while people with FM attempt to put their symptoms in the background to maintain some normalcy in their lives, they nevertheless find it hard to do so when they have to prove that they are legitimately sick to warrant disability benefits.
The stress of their living with FM is further intensified, as participants in this study reported, because the restructuring of the present health care system changes what services will be available and accessible to them. When additional health care budget dollars are in short supply, it is the mandate of the government to decide carefully which health care resources it should fund and which applicants are eligible for disability benefits. Such decisions have the potential to further reduce funding for people with FM. This uncertainty increases participants' stress of living with FM, as they must live in fear that what disability funding they have may not always be available to them.

*Implications*

The foregoing discussions have indicated the various ways in which the influence of social, political, and health care contexts may shape individuals' experiences of living with the condition. According to Toombs, Barnard and Carson (1995), “social, cultural and political responses to limitation and dependency shape individual experience and influence the possibilities for personal transcendence” (p. 54). The findings of Toombs et al. and Thorne (2000) on chronic illness, and Henriksson and Burckhardt (1996) on FM, suggest that it is important for health care providers to analyze the broader environmental context within which people with FM live their illness in order to provide better care. Henriksson and Burckhardt (1996), Raymond and Brown (2000), and Sylvain and Talbot (2002) all advocate this approach, and informants in this study seemed to agree that this would improve their situation. When we consider the findings of this study in light of other work on invisible illnesses (Asbring & Narvanen, 2002, 2003; Fitzgerald & Paterson, 1995; Lubkin & Larsen, 2002), it seems evident that individuals with FM would feel better supported if health care professionals helped them deal with the social
stigma attached to their condition. This study's findings offer additional support for the Bernard et al. (2002b) suggestion that there is a need for health care providers to educate others about the nature of FM and the importance of understanding client experiences related to living with this condition. Such education ideally can enable others to provide people with FM with the emotional support they need to cope with their condition.

As I have noted previously, most people with FM seek a combination of treatment modalities such as medications, naturopathy, homeopathy, and massage therapy sessions to manage their symptoms. The BC Medical Services Plan currently covers few of these treatment modalities. This study observes, as do other studies on FM (Hughes, 1999; Soderberg & Lundman, 2001; Sturge-Jacobs, 2002), that when people with FM are unable to work, or need to cut down their working hours, this reduction affects their financial resources, which in turn affects their ability to afford most treatment modalities. This is a "double whammy": decreased resources together with increased costs greatly increased the participants' stress in living with the condition. As Thorne and Paterson (2000) suggest, there is a need for further research to elicit the perspectives of people living with chronic illness who have inadequate financial resources, in order to help them to better manage their conditions. This is certainly applicable in the case of many people living with FM, as participants in this study have pointed out.

Finally, as Relman (1990) notes, in a financially constrained health care system that cannot fund all medically appropriate care for everyone, it may be impossible to find a more equitable allocation of available resources to provide necessary services for all those needing them. This is especially so when the majority of the treatment strategies for FM have little evidence of long-term benefit and it may be difficult for the present health
care system to justify spending its limited resources on a condition whose very existence is currently debated. Bernard et al.’s (2002b) suggestion, together with the findings of this study, seem to suggest that further research may assist in determining the treatment modalities and programs that are most cost-effective and efficient for people with FM. These may ultimately give direction for policy and program planning in deciding how best to allocate the scarce resources.

Summary and Conclusions

This study relies on the interpretive descriptive method as described by Thorne, Reimer Kirkham and Macdonald-Emes (1993) to elicit the experience of fibromyalgia from the perspective of those living with the condition. The researcher has employed purposive theoretical sampling, and has collected the data by means of in-depth, semi-structured interviews with eight participants ranging in age from 31 to 79 years. Data collection and analysis occurred concurrently, using a constant comparative inductive analytic method. The analytical framework guiding this inquiry was derived from the existing literature that addressed the experience of living with the condition. This body of literature was then compared with the findings of the current study to capture the essence of living with the phenomenon within the general context of participants’ lives.

The findings of this interpretive descriptive study have demonstrated key aspects of individuals’ experiences of living with FM. One of the three major themes is living with the symptoms of FM. This category had sub-themes including the wide range of complex, varying symptoms with their numerous consequences ranging from physical, psychosocial, familial, career, and recreational effects to economic impacts. The second theme, management of FM, identifies key aspects of the management process: striving to
achieve and maintain a balance, and utilizing of support networks. The third theme encompasses the social and political contexts within which individuals with FM live and manage their illness. I have discussed the study’s findings within these three themes in light of the current knowledge of both FM and chronic illness, and have identified implications for nursing practice, research, and education.

As researchers and practitioners increase their understanding of FM, the complexity of this illness and its challenges are evident. Clearly there is much to be learned from exploring the experiences of individuals, and several areas for further research can be identified: the role of social support in FM; the value of self-help versus professionally-led support groups; the process around decision making among the various strategies for maintaining balance in the management of FM; and the additional impact of living with the condition while having only limited financial resources available.

Some of the FM and chronic illness literature suggests that we explore beyond the bio-medical model and take into account the physical, mental, emotional, spiritual, and social contexts of illness. Participants in this study would endorse such a viewpoint. In fact, they would tend to favour holistic individualized approaches to the diagnosis and care of people with FM, and, as well, a collaborative model for the relationship between patient and health care provider. These findings have called attention to some important issues in health care provider and patient relationships.

In spite of the limitations of this study and an inability to generalize its findings to other contexts, this interpretive descriptive study has both affirmed many of the research findings of earlier fibromyalgia studies, and contributed to an expanding body of knowledge about this health condition. The participants in this study were able to provide
the researcher with some rich insights into the phenomenon of living with fibromyalgia, illustrating some important implications for nursing education and practice as well as raising future questions for research. The findings of this study suggest that certain crucial areas, such as the relationship between health care providers and people with fibromyalgia, are of great importance to the latter, but are still insufficiently understood, and therefore require further examination. In the interim, those who must live with fibromyalgia must also live, unfortunately, with the knowledge that theirs is a chronic health condition encompassing unknown etiology, problematic diagnosis, and complex symptoms involving major impact and multidimensional treatment that deserves better understanding by both health care professionals and the general public.
REFERENCES


Hadler, N.M. (1996a). If you have to prove you are ill, you can't get well: The object lesson of fibromyalgia. *Spine, 21*(20), 2397-2400.


TENDER POINT SITES: 1990 CLASSIFICATION CRITERIA

1. Occiput at the suboccipital muscle insertion.
2. Low cervical, at the anterior aspects of the intertransverse spaces at C5-C7.
3. Trapezius, at the midpoint of the upper border.
4. Supraspinatus, at origins, above the scapula spine near the medial border.
5. Second rib, at the second costochondral junction, lateral to the junctions on the upper surfaces.
7. Gluteal, at the upper outer quadrants of buttocks in anterior fold of muscle.
8. Greater trochanter, posterior to the trochanteric prominence.
9. Knees, at the medial fat pad, proximal to the joint line.

(All sites are bilateral)

I hope you will consider participating in this study that will contribute to better understanding of the experience of living with fibromyalgia. If you are interested in participating or would like more information about this study, please phone me or my thesis supervisor, Dr. Carol Jillings at the numbers listed above.

Thank you for your cooperation.

Yours sincerely

Margaret Cunningham, RN, BSN
APPENDIX D

Participant Consent Form

Study title: Individuals’ descriptions of living with fibromyalgia

Researcher: Margaret Cunningham, R.N., M.S.N. student,

Office contact number: 604 822-7459

Faculty Advisor: Dr Carol Jillings, Associate Professor, University of British Columbia,

School of Nursing, contact telephone number 604 822-7479.

I understand that this study, part of Margaret Cunningham’s thesis for her Master of Science in Nursing Degree, aims to understand what it is like to live with fibromyalgia. I am aware that I will be asked to describe my experiences in living with the condition.

I understand that if I agree to participate in this study, I will be asked to participate in two tape recorded interviews with the researcher, Margaret Cunningham, at places and times that are convenient for me. Each interview will last one or two hours. I understand that a second interview may be required to validate or clarify answers from the first interview. I consent to have these interviews audiotaped and transcribed by a typist.

I understand that any information obtained during the interviews will remain confidential and that the names of the participants will not appear in any report or publications related to the study. I also understand that all audiotapes and transcripts will be coded and kept in a locked cabinet. The findings of the study will be shared with me. The results of the study will be reported in Margaret Cunningham’s Masters’ thesis, and may be presented in professional publication or at professional conferences or be used in future studies.

I understand that the audiotapes will be destroyed once transcribed and the written reports will be preserved with no identifying markers or names to ensure anonymity to permit the possibility of using the data for future data analysis.

I understand that I am not obliged to participate and are free to withdraw from the study at any time. I also understand that any refusal on my part to participate will in no way jeopardize or influence any care that I may receive now or in the future. There are no known benefits or risks for participating in the study. However, the interview in facilitating my recounting of my experiences to an attentive listening researcher might be helpful to me. It is also possible that talking about some of my life experiences may be emotionally upsetting for me. If I become emotionally upset, I may ask for the interview to be stopped.
I have been given the opportunities to ask whatever questions and the answers have been given to my satisfaction. I understand that if I have questions about the study, I may contact Margaret Cunningham at 604 822-7459 or Dr. Carol Jillings at 604 822-7497.

I understand that if I have any concerns about the way the study is conducted or about my rights as a research subject I may contact the Research Subject Information Line at 604 822-8598.

I acknowledge the receipt of a copy of this consent form for my record.

Participant’s signature Date

Signature of a witness Date
APPENDIX E

Demographic Data

Informant ID Number ____________________________

Age ________

Occupation ____________________________

Length of time living with fibromyalgia ________________

Current status with fibromyalgia ________________________________

Any other existing disease or health issue_________________________
APPENDIX F

Interview Guide

Questions:

How long have you had fibromyalgia?

Tell me what it is like for you to live with fibromyalgia

Can you describe your experiences of living with fibromyalgia?

How do you cope/live with this illness? What changes have you had to make?

What are your feelings related to the illness?

Prompts:

Can you tell me more....

So what you’re saying is…

What were your feelings…

What was that like for you?

Is there anything else I should ask or you would like to add on?

Is there anything else you wish to tell me?